

UNIVERSITY OF ALBERTA

CHILDREN'S RECOVERY FROM DAY SURGERY

BY

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A THESIS SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
AND RESEARCH IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF MASTER OF NURSING

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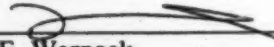
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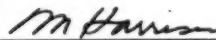
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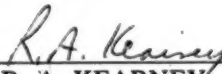
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Abstract

The topic of this thesis research is children's postoperative pain. The first of the two papers in this document is a literature review about factors affecting how children perceive and express pain, and about factors influencing the assessment and treatment of children's postoperative pain. Gaps in knowledge and areas for further research were identified in the paper. These included the need for further investigation of pain trajectories and recovery patterns following pediatric day surgery. The second paper is a report of original research on postoperative pain and pain management following children's tonsillectomy day surgery. Forty six children (aged 5-16) were assessed for seven days following surgery. Children's daily pain, daily analgesic administration patterns, and care giving experiences of parents were assessed. Findings indicated that post-tonsillectomy pain followed an average trajectory of moderate to intense pain for the first few days after surgery, declining thereafter. Analgesics were prescribed and administered to children in insufficient amounts. Postoperative care was provided by parents who were ill prepared. Moreover, the information provided to children and parents about recovery from tonsillectomy and pain management was inadequate. The results of this study suggest areas of children's health care that need to be improved. They also provide information about the pattern of recovery from tonsillectomy as well as children's own reports of postoperative pain.

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Overview of Thesis Project

This brief paper serves as an introduction to my thesis research and as a guide to the materials included in this document. The document consists of the overview as well as two manuscripts. I have used the paper format for the thesis, one alternative recommended by the Faculty of Graduate Studies at the University of Alberta. This means that several manuscripts have been written about my research topic.

Manuscript A, "Postoperative Pain in Children: A Review of the Literature," pertains to:

- factors influencing children's perception and expression of pain, and
- assessment and treatment of children's postoperative pain

Manuscript B, "Children's Recovery From Day Surgery," is a report of the original research that I have conducted for my thesis. The topic is postoperative pain and pain management following children's tonsillectomy in day surgery. I have used the format recommended by the journal to which I plan to submit this manuscript. The appendices provide important information that could not be included in the manuscript.

Background To The Research

My interest in children's pain arose from my clinical experience with children and is grounded in my belief that unnecessary pain is unwarranted and unethical. I am defining unnecessary pain as pain that can and should be treated given our present state of knowledge. Postoperative pain is of concern because it can have harmful physiological and psychological effects on children's health and subsequent development. My clinical experience led to an increasing concern about assessment and treatment of children's pain and to my academic inquiry about the topic.

The literature on children's pain informs us that the ways in which children perceive and express pain are embedded in a complex matrix of interrelated factors as predicted by pain theories. In the first manuscript of this document, a prominent view of pain was described. This is the theoretical underpinning which guided this thesis study and most of the research discussed in the literature review.

In this thesis report, I am viewing pain as a multidimensional subjective phenomenon that affects the totality of the human, and as such it can only be fully comprehended by the individual experiencing it. This view is based on the definition of pain issued by the International Association for the Study of Pain (1979) which stated, "pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (p. 250).

The factors discussed in the first manuscript included:

- children's age,
- previous pain experience,
- gender,
- family upbringing,
- clinician baseline pharmacological and developmental knowledge,
- pain assessment practices, and,
- pain treatment barriers.

A summary of the gaps in knowledge and areas requiring further research included:

- determining the effects of family, and social role expectations;
- determining the effects of past negative pain experiences, emotion, and current coping or catastrophic pain behaviors on how children perceive and express pain;
- determining postoperative pain prevalence rates, and;
- developing strategies for improving attitudes about pain and children.

While research is required to address the aforementioned gaps in our knowledge, another area identified as requiring urgent investigation is postoperative

pain experienced by children undergoing procedures in day surgery. This population was of particular concern for several reasons. First, we lack knowledge about children's recovery patterns and pain trajectories following surgery, including day surgery. Second, we lack knowledge about how parents are handling the responsibilities of providing postoperative care and pain management.

Some recent research informs us that children have significant pain 48 hours after day surgery and that parents fail to administer adequate pain medication even when they assess their children to be in pain (Finley, McGrath, Forward, McNeill & Fitzgerald, 1994). Limitations of the research included use of parent's rather than children's reports of pain, small sample sizes that limited subsequent analysis, and lack of follow-up beyond 48 hours (a time when children reported intense pain).

The findings reported in the literature combined with my observations about changes to our local health care system made me concerned about the state of pain assessment and treatment, particularly for children undergoing day surgery. These concerns stemmed from my previous experience in preparing children and families for surgery, and from my knowledge about providing postoperative care to children for procedures now routinely performed in day surgery. As well, I was aware of some issues and problems faced by adults who had day surgery. Furthermore, the experience I gained in participating in a pilot project evaluating a local day surgery program made me aware that some parents experienced difficulties in providing postoperative care to their children, and that some children received inadequate postoperative analgesics.

I therefore, designed a study to assess the trend in children's pain over seven days following day surgery, and to test the hypothesis that children who received a standardized analgesic regimen would have lower child rated pain intensity scores over the seven day postoperative period than children who received the usual day surgery routine. The analgesic regimen was developed in collaboration with the pharmacy department and was based on recommended therapeutic doses for acetaminophen and codeine as advocated by the International Association for the Study of Pain. A standardized teaching protocol was also designed to provide subjects receiving the proposed analgesic regimen with information about the cycle of pain, pain assessment, and analgesic administration. The controlled drug study was however abandoned because surgeons saw no need for a change in practice.

I then considered alternative research questions including the determination of prevalence rates of postoperative pain following pediatric day surgery. The epidemiological design required consecutive sampling of large numbers of subjects for which there were insufficient resources. Because all children having day surgery were to be sampled within a defined period of time, several different assessment tools would be required for different age groups of children. These issues complicated design and data analysis and a prevalence study was therefore not considered feasible.

The research that I did undertake was a descriptive study of postoperative pain and care provided by parents. Rather than choosing a diverse group of children and surgeries, as had been done in past research, I have targeted school aged children and

tonsillectomy, one of the most common and painful day surgery procedures. The purposes of the study included description of:

- children's postoperative pain and other outcomes over time;
- administration of analgesics, and;
- parent's views and concerns about providing postoperative care.

The study was conducted over one four week period and consecutive sampling was achieved for all qualifying cases of tonsillectomy in our region. The tools used for data collection included

- a two part questionnaire;
- medication log, and;
- 100 mm VAS.

In retrospect, it was fortunate that the original experiment could not be undertaken since there were important issues that were uncovered with this descriptive study. Results obtained indicated that: 1) children experienced moderate to severe pain following tonsillectomy and this declined to a mild level, 2) parents reported feeling ill prepared for their care-taking roles, 3) children were prescribed and administered inadequate amounts of analgesics postoperatively, and 4) that the quality of information given to children and parents was inadequate.

In addition to changes required for postoperative analgesic prescription, the findings also suggest that improvements are required to the existing educational health care services offered to children receiving day surgery. The types of postoperative information provided, the timing, and the mode of information delivery are three areas that require attention, perhaps through the development of a pediatric day surgery education program. The literature on patient education informs us that adults learn what

they want to learn, that diversity of sensory mediums attends to individual differences for learning, and that reinforcement of learning over time optimizes retention of information. As well, we know that increasing the confidence of parents for parenting reduces their anxiety and helps prepare them for their care taking roles.

In this study, parents wanted general information about tonsillectomy and information about how to prepare for it preoperatively and postoperatively. A wide range of innovative communication mediums are currently available that provide opportunity for development of creative educational strategies and they include computer on-line and interactive videos. Such mediums may be ideal for teaching parents and children about the cycle of pain and increasing their understanding about the benefits of analgesic administration. As well, the various mediums may be used during the preoperative and postoperative periods to help equip families with required information. These innovative strategies go beyond the typical educational approaches of providing written and verbal information on the day of the children's day surgery, and they may be more appropriate and more effective given current resource availability. Such mediums offer a broad spectrum for access to information. Diversity of informational resources also allow for individual differences in preference for educational strategies.

In addition to general information, parents also required detailed information about postoperative care and pain management. On the day of surgery, parents can be asked about their children's pain histories. This knowledge can then be integrated into a written step by step instruction guide for pain assessment and analgesic

administration. Step by step instruction may also help parents to deal with negative postoperative outcomes should they occur.

Findings also indicated that parents and children valued and desired personal supportive contact. The daily follow-up telephone calls provided opportunities for parents to ask questions specific to their care taking roles and their children's recovery. It is recommended, therefore, that some traditional services affected by health care cut backs in our region be reinstated and extended. These include preoperative contact and postoperative telephone calls made during the course of surgical convalescence to all families, including those from the rural area. While the cost of some of the suggested innovative and support programs would be very low, others would be more costly and perhaps reserved for a small percentage of the population.

Additional Information

All information about the research are contained in Manuscript B and the four appendices. All tables and figures contained in the document are discussed in Manuscript B except some of the results contained in Tables A8, A9 and A10 (all found in Appendix A) which will be discussed here. Results of the third question in Table A8 indicated that on the last day of follow-up, the mean score for parental preparation for caretaking (n=44) was 6.6 on a scale of 1 (completely unprepared) to 10 (totally prepared). This finding seems to overestimate parental perceptions of caretaking obtained from some of the open ended questionnaire items. Differences in response may be because the word, preparation, used in the 10 point questionnaire item was ambiguous and parents did not understand its meaning.

Table A9 refers to the ANOVA results for gender on pain intensity over the seven days. The non significant result supported other study findings. The effect of age on pain intensity was not analyzed because of the small numbers per age category.

Table A10 provides a summary of the analgesic and pain rating information for 39 cases over the seven day follow-up period. Included are the weights of the children in kilograms, discharge prescription, recommended therapeutic amounts of analgesics per 24 hour period, and daily amounts of analgesics administered compared with daily pain ratings. All analgesic amounts provided in this table were calculated by converting the prescribed and recommended amounts of analgesics to IM morphine equivalents/kg.

Appendix D contains the parent and child responses to each of the open ended questionnaire items included in Questionnaire 2. Content analysis of these interview data provided the frequencies for the 17 negative postoperative outcomes identified in Table 3.

References

Finley, G. A., McGrath, P. J., Forward, S. P., & Fitzgerald, P. (1996). Parents' management of children's pain following 'minor' surgery. Pain, 64, 83-87.

International Association for the Study of Pain. (1979). Pain terms: A list with definitions and notes on usage. Pain, 6, 247-252.

Manuscript A

Postoperative Pain in Children: A Review of the Literature

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Postoperative Pain in Children: A Review of the Literature

Postoperative pain is described as one of the most common childhood pain problems (Schechter, 1989). The physiological and psychological ramifications of unresolved postoperative pain in children are numerous and they include the over production of stress hormones that contribute to prolonged surgical healing and hemodynamic instability (Schechter, Berde & Yaster, 1993). Development of anxiety, fear, distress reactions, and subsequent avoidance or phobic behaviors are also thought to occur as consequences to negative experiences of pain for some individuals (Philips, 1987; Rachman & Lopatka, 1988).

Undertreatment of postoperative pain in children is reflective of the complexity of pain and is the result of many interrelated factors. The pediatric pain literature provides insight into the current state of knowledge concerning the relationship of these factors with how children perceive and express pain, and provides guidance for further research investigation. Thus, the purposes of this paper are to present an overview of the literature with a view to define pain, present a prominent pain theory, discuss the etiology and incidence of pain in children, identify factors that influence how children perceive and express pain, and identify factors that either facilitate or thwart effective postoperative pain assessment and treatment.

Definition of Pain

Pain is often characterized as a sensory reaction to noxious stimuli, however, it is well acknowledged that the perception of pain is influenced by factors that vary across time and individuals. In children, individual differences in how pain is perceived and

expressed are also influenced by changing developmental, situational, and emotional factors (McGrath, 1989). Thus, each child will perceive each pain experience differently, and no two children will have the same pain experience.

No universal definition of pain exists. However, a definition that is increasingly adopted by clinicians and researchers comes from the International Association for the Study of Pain (IASP) (1979) which defines pain as, "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (p. 250). While it is acknowledged that the IASP definition helped broaden the view of pain as being subjective in nature, the definition is nonetheless incomplete because it is limited to those who are able to "describe" their pain. Infants, toddlers, and other individuals who are unable to communicate their pain are therefore not adequately represented by the IASP definition of pain.

Historically, various pain conceptions have generated different pain theories and provided the framework for pain research and treatment approaches (Robinson-Wolf, 1980). The next section describes one such pain theory.

The Gate Control Theory of Pain

In 1965, Melzack and Wall advanced the "gate control" theory of pain which put an end to the predominant anatomical view of pain which they termed the "specificity" theory. The authors showed that data did not support the specificity theory because the theory was too narrowly focused and insufficient in explaining pain outside of sensory stimulation and reaction. Rather, they proposed the integration of multiple dimensions or components that influence pain perception (Melzack & Wall, 1988). Sensory-

discriminative components of the nociceptive stimulus and the affective-motivational and cognitive-evaluative components are now thought to be the dimensions that underlie behaviors aimed at modifying reactions to internal or external stimuli. Therefore, physical sensation, cognitive appraisal, concentration, emotions, memories of prior experiences, prior learning, cultural and familial attitudes, expectations, suggestions, and anxiety all act to open or close the gate (a group of highly specialized T cells found in the substantia gelatinosa located in the dorsal horn of the spinal column) (Melzack & Wall, 1988). Opening the gate serves to increase the level of pain perception while closing the gate decreases it. Effective pain management strategies aim to close the gate (Melzack & Wall).

Postoperative Pain in Children: Etiology and Prevalence

Pain as a result of surgery is usually described as acute pain which results from surgical tissue excision and damage. Postoperative pain is intense in quality but intensity gradually diminishes with surgical healing (Melzack & Wall, 1988). Factors that influence the intensity, quality, and duration of postoperative pain include: the site, nature, and duration of surgery; the type and extent of the surgical incision; and associated tissue trauma (Melzack & Wall). Common types of surgical procedures performed on children that result in acute pain involve excision of soft tissue and include urological, ear nose and throat, and abdominal procedures.

Research done in the past 13 years indicates that hospitalized children (Bennett-Branson & Craig, 1993; Johnston, Abbott, Gray-Donald & Jeans, 1992; Mather & Mackie, 1983), and non-hospitalized children (Finley, McGrath, Forward, McNeill &

Fitzgerald, 1996) experience moderate to severe postoperative pain in the first 48 hours after surgery because their pain is under-assessed and undertreated. While such reports are informative any conclusions that can be drawn must take into consideration study design weaknesses including use of small sample sizes, wide range of ages and diagnosis, short duration of follow-up, and inconsistencies in obtaining self report of pain from the children themselves. Furthermore, researchers have not employed epidemiological designs to ascertain postoperative pain prevalence rates in children, again limiting study conclusions and study implications or recommendations (Zeltzer, Barr, McGrath & Schechter, 1992).

Factors That Modify Children's Perception and Expression of Pain

While the intensity of the noxious stimulus is proportional to nociceptive afferent input, each child will perceive, understand, communicate, and cope with pain differently (McGrath, 1990). Researchers have identified several factors that are thought to influence how children perceive and express pain and they include children's age, gender, previous pain experience, and family upbringing. Each of the factors are discussed below.

Age. It is generally accepted that children define, interpret, and express pain in terms of their age and cognitive levels. Studies that have used developmental frameworks as part of their research methods or as adjuncts to interpretation of study findings lend credence to this assumption (Gaffney & Dunne, 1986; Alex & Ritchie, 1992). Cognitive ability may affect children's beliefs about and responses to pain since

it is thought that children of varying ages interpret and react to fear and anxiety differently (Reissland, 1983).

In one clinical study, younger children were found to be more anxious, to display more distress, expect more pain, and report greater pain intensity and distress than older children (Lander & Fowler-Kerry, 1991). The findings were explained in terms of younger children's inability to see any purpose to pain and their limited repertoires of past pain experiences (Lander & Fowler-Kerry). Younger children may also lack ability to exercise control over themselves or their immediate environments. It may also be that younger children are more vulnerable to the stress associated with separation from parents and stress associated with the surgical experience (Visintainer & Wolfer, 1975).

With age come increased learning opportunity, increased freedom for independent decision making, and increased success, all leading to ability to control pain and anxiety through increased coping skills (Craig & Bennett-Branson, 1993). However, older children have not always demonstrated decreased anxiety and reduced pain intensity scores. It is reported that higher postoperative anxiety ratings (Ellerton & Merriam, 1994) and higher detention and overnight admission rates (Glazebrook & Sheard, 1994) occur in older verses younger children having daysurgery. This may be because older children are not adequately prepared for day surgery, or it may be because adults overestimate adolescent children's abilities to cope in this particular situation (Glazebrook & Sheard). More research is required about older children's responses to pain in varying situations.

Age is also regarded as a predictor of the quality of pain assessment and treatment. Both the aged (Melzack, Abbott, Mulder & Davis, 1987) and the young (Mather & Mackie, 1983) are likely to experience poor pain management. Inadequate treatment of children's pain has been found to be associated with misconceptions regarding pain and children (Schechter, 1989). Such misconceptions relate to the erroneous belief that children, because of their age, do not remember pain and thus do not experience long term negative effects, or if they do, they do not experience it as intensely as adults (Eland & Anderson, 1977). Other issues include children's dependent positions on adults, power inequalities, lack of freedom or inability to speak out or represent themselves, and the lack of power to be believed as legitimate providers of credible knowledge. A functioning of any one of these factors may be associated with findings of children not receiving adequate analgesics as compared to adults even though they often undergo similar surgeries and are exposed to repeated painful procedures (Mather & Mackie, 1983; Tesler, Wilkie, Holzemer & Sevedra, 1994). More research is required that provides insight into how children of varying ages perceive pain especially in situations where pain is normally experienced (Lander & Fowler-Kerry, 1991). Involving children as active participants, and use of multiple pain assessment tools such as self report, observation, and physiological indicators may also assist in obtaining legitimate assessments of pain.

Previous pain experience. Past pain experience is also thought to influence children's perceptions and expressions of pain. Their memories of and subsequent expectations about the quality of the pain sensation, the meanings attached to it, and

abilities to cope with or predict what will happen all influence how children think about pain and how they express it (McGrath, 1990). With age and repeated pain experience (Lander & Fowler-Kerry, 1991, McGrath), children's abilities to tolerate pain increases or decreases. It may be that the quality of the past pain experience rather than the frequency of experiences has a greater impact on how children interpret pain for each subsequent experience. Past pain experiences that are perceived to be positive serve to increase coping abilities thereby decreasing anxiety and decreasing expectations of pain (Brown, O'Keefe, Sanders & Baker, 1986; Lander & Fowler-Kerry, 1991).

Conversely, past pain experiences may contribute to the development of anxiety or distress for subsequent pain experiences. For children experiencing repeated painful procedures, expressions of pain may be reflective of regressive behaviors which represent reactions to unanticipated fear of the unknown or anticipated fear of the known (Hart & Bossert, 1994).

The effects of past hospitalization and anxiety on pain have also been investigated. While some researchers report that previously hospitalized children experience more upset and anxiety, and presumably more pain (Jackson, Winkley, Faust, Cermak & Burt, 1953; Wachtel, Rodrigue, Geffken, Graham-Pole & Turner, 1994; Watt-Watson, Evernden & Lawson, 1990), others report that previously hospitalized children are less upset, and less anxious (Ellerton & Merriam, 1994; Tiedeman & Clatworthy, 1990; Wells, 1983). These disparate findings may be attributed to type of tools for measuring anxiety and pain, the quality of past pain experiences, or failure to control for important situational variables such as parental modeling effects.

Gender. While it is commonly reported that gender differences exist in pain, it is at times unclear whether these differences occur in pain expression, pain perception, or both. Recent literature suggests that no gender differences exist in children's ratings of pain intensity but that differences exist in males' and females' expression of pain (Johnston et al., 1992; Lander, Fowler-Kerry & Hargreaves, 1989). For instance, in one recent study, boys were found to be more anxious than girls postoperatively and they were found to cope less effectively with pain especially outside the clinical setting (Tiedeman & Clatworthy, 1990). Researchers have also found that females report their pain more frequently than males, use more pre-coping strategies, and express pain in terms of verbal aggression (Brown et al., 1986). Males on the other hand, underestimate their pain, use more control measures, or express pain in terms of physical aggression (Fowler-Kerry & Lander, 1991; Savedra, Gibbons, Tesler, Ward & Wegner, 1982).

Variation in gender differentiated pain behavior may be due to societal expectations and norms rather than actual gender differences in pain perception. Societal norms and expectation support and reinforce overt pain expression in females and stoic behavior in males (Tiedeman & Clatworthy, 1990). In cases where gender differences in pain intensity are reported, use of gender biased pain assessment tools, use of induced pain rather than naturally occurring pain, and experimenter expectations of gender role behavior may have accounted for the findings. Future research in children's pain therefore needs to remain sensitive to potential gender related biasing and perpetuation of gender differentiated pain assessment and treatment.

Family. The expectations of, and the ways in which parents respond to their children's overt indications of pain have profound influence in modifying children's perceptions of pain and influencing how they learn and respond to it (Lumley, Melamed & Abeles, 1993). As well, the ways in which parents and other family members speak about, display, and react to their own and another's pain provides the child with a basis for interpreting family norms, shaping their attitudes about pain, and determining the meaning given to the notion of pain (McGrath, 1990). The modeling effect that parents have on their children may therefore account for the finding that parental anxiety is predictive of children's anxiety (Manne, Jacobsen & Redd, 1992). For instance, existing parental anxiety levels, coping behaviors and parental expectations of their child's pain for each situation may act as modeling influences for children's subsequent pain behaviors. Such variables may provide predictive knowledge for children's assessment of pain, however more research is required to test these variables.

The family usually provides a safe and nurturing environment for the child. This may explain why 99% of children wish a parent to be present during painful procedures (Ross & Ross, 1984). Promoting family centered care and reducing the amount of time children spend in hospitals are strategies meant to reduce children's anxiety and maintain family integrity.

Factors That Influence Management of Post-operative Pain

Factors influencing children's postoperative pain management include methods of pain assessment, beliefs and attitudes regarding pain and children, clinician knowledge

about analgesics and child development, and methods of preparing the child for the surgical experience. Each of these factors are discussed below.

Pain assessment. Accurate assessment of pain is the cornerstone for effective pain management. Various developmentally appropriate tools exist that integrate behavioral, physiological, and psychological indicators for assessing different dimensions of pain in children. Currently, subjective self report is considered the gold standard for assessing pain. Children as young as three can provide accurate and reliable description and location of their pain, and are able to successfully use simple pain assessment tools (Beyer & Wells, 1989). Children as young as five have also demonstrated success in using direct scaling techniques such as visual analogue scales (McGrath, 1990).

Nonetheless, parents, nurses, and doctors have been found to rely heavily on children's behavioral cues as primary indicators for assessing the existence of pain (Nethercott, 1994; Tesler et al., 1994; Wachtel et al., 1994; Watt-Watson et al., 1990).

Furthermore, parents learn to use "trial and error" strategies for managing children's pain (Gedaly-Duff, & Ziebarth, 1994). This may be because adult care providers use knowledge and past experience combined with their own personal beliefs about pain and children to determine if the child's pattern of behavior fit their expectations (Nethercott; Watt-Watson et al.).

It is reported that clinicians' decisions to administer analgesics are not related to children's reports of pain (Powers, 1987). Similar findings are also reported for parental pain assessment and treatment decisions. For example, in Gedaly-Duff & Ziebarth's (1994) study, mothers reported feeling uncertain as to the intensity of their

children's pain and they questioned whether their children's pain behavior cues were more reflective of "attention-getting" behaviors rather than reflective of actual pain. Finley et al. (1996) also reported that mothers often gave inadequate dosages of analgesics to their children even when they assessed their children to be in pain. Undertreatment of children's pain may therefore be due to misinterpretation of children's pain cues and drawing of premature conclusions regarding the nature of the cues. Lack of confidence in one's own assessment skills, lack of informational resources, or fear and uncertainty may also interfere with effective pain treatment practices. As well, undertreatment of children's pain may be due to the reliance on solitary rather than multi pain assessment approaches, ignoring children's present states of references (such as situational factors, past pain experiences, and emotional states); reluctance to use or believe in children's self report, or reluctance to use validated, reliable and developmentally appropriate pain assessment tools (Ellis, 1988; McGrath, 1989).

Assumed beliefs and attitudes regarding pain and children. Incorrect assumptions and attitudes act as powerful barriers to effective pain management (Gillies, 1993) and they are cited as the main reasons for clinical undertreatment of postsurgical pain in children (Schechter, 1989). For example, clinician and parental assumptions regarding the metabolization rate of analgesics in children, and associated concerns over respiratory depression and overdosing have been found to result in persistent undermedication practices despite evidence to the contrary (Gedaly-Duff & Ziebarth, 1994; Powers, 1987; Schmidt, Eland, & Weiler, 1994; Spicher & Yund,

1989). In addition, attitudes arising from personal values also result in undertreatment of children's postoperative pain. Examples of such attitudes include beliefs that children (especially boys) should "tough it out", pain builds character and inner self-control, and narcotics cause addiction (Schechter, 1989).

While incorrect assumptions can be corrected with educational interventions, attitudes are much more difficult to resolve and this may account for such long term and persistent practices despite educational interventions (Fishbein & Middlestadt, 1987). Development of educational programs based on human motivation and change theory may assist to change attitudes, contribute to sustained change, and improve clinical pain assessment and management practices. Development of such strategies and educational programs can be achieved, for example, through the use of both qualitative and quantitative research methodology using the theory of Planned Action and the principles of social marketing as guiding frameworks (Ajzen, 1985).

Knowledge about analgesics and child development). Knowledge about analgesic administration is an important component of effective pain management. Inadequate pain management arises due to incomplete, incorrect, or absence of pharmacological information possessed by the clinician, nurse, or parent (Lander, 1990; Powers, 1987; Schmidt et al., 1994; Tesler et al., 1994; Tyler, 1994; Watt-Watson et al., 1990, While & Wilcox, 1994).

For instance, the pattern of prescribing postoperative analgesics (early predominance of opioids then shifting to nonopioid analgesics) is not reflective of current knowledge regarding the benefits of combining opioids with nonopioids (Tesler

et al., 1994). Deficiency or inaccuracy of pharmacological knowledge is also reflected, in persistent adherence to analgesic administration on a PRN (as needed) bases rather than weight appropriate dosages on a 24 hr. basis (Tesler et al., 1994). The consequences of PRN administration have been found to contribute to unstable blood levels of the drug due to prolonged dose intervals, to cyclic recurrence of pain and anxiety for the child, and to eventual escalating analgesic administration (Mather & Mackie, 1983; Rauon & Holman, 1989; Schmidt et al., 1994; Twycross, 1984; Yaster, Sola, Pegoli & Paidas, 1994).

Undermanagement of children's pain may also be due to inadequate knowledge of children's normal growth and development or in failure to apply this knowledge when assessing and treating children. Researchers have found that physicians and nurses either under or overestimate children's cognitive abilities (Perrin & Perrin, 1983), and that they underestimate children's pain intensity scores (LaMontagne, Johnson & Hepworth, 1991). Erroneously assessing children's cognitive abilities may lead to perpetuation of assumptions and situations where pain is chronically mismanaged. More qualitative type research is thus required that explores children's pain experiences from their perspective, and describes the meanings children of varying ages give to their experiences.

Psychological preparation. It is well acknowledged that surgical patients experience more anxiety than medical patients regardless of severity of disease (Volicer, 1978; Volicer & Burns, 1977), and that children, in particular, are more psychologically vulnerable to the effects of the surgery experience (While & Crawford,

1992). Anxiety due to hospitalization and impending surgery lowers children's levels of self-esteem and increases their levels of stress, psychological upset, and fears either to real or imagined threats (Visintainer & Wolfer, 1975). Surgical preparatory programs are designed to prepare children psychologically for the surgical experience, lower anxiety levels of the children, provide parents and children with information, and facilitate anesthesia induction and surgical recovery (Bates & Broome, 1986; Elkins & Roberts, 1983).

Currently, no surgical preparatory programs exist in our region. Decisions to eliminate preparatory programs, in other areas, arise from priorities for cost containment and varying definitions of cost savings and program effectiveness (While & Crawford, 1992). The repercussions of not psychologically preparing children for surgery need to be further assessed given the changes to traditional surgical services. This is especially relevant for children who undergo surgery on a day surgery basis.

In our region, more surgery is performed on children on a day surgery rather than in-patient basis. Given the scarcity of research in this area, little is known about the quality of preparation provided children having day surgery and their parents, and little is known about the subsequent occurrence of postoperative pain and other common surgical outcomes. More community based and longitudinal pain research are thus required to determine the impact health care changes have on children's pain.

Screening or pre-identifying children who are at increased risk for psychological trauma following surgery may also be an area for further investigation. Furthermore,

criteria for day surgery program effectiveness that is considerate of outcomes for the child rather than for the institution need to be clarified and decided upon.

Conclusion

In summary, multiple factors have been identified that influence how children perceive and express pain and that influence how postoperative pain in children is assessed and treated. Gaps in knowledge and areas for further research have also been identified. In order to advance knowledge and improve practice it is important that such gaps be addressed. For children having surgery this is important because of the deleterious short and long term effects of unresolved postoperative pain. Research into children's pain must also take into consideration changes to current health care services. Advancing theoretical understanding of children's pain and keeping research relevant to changing health care will serve to optimize the assessment and treatment of children's postoperative pain, help children and their families prepare and deal with pain as it is experienced, and reduce the occurrence of undertreated pain irrespective of contextual circumstances.

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Manuscript B

Children's Recovery From Day Surgery

Children's Recovery From Day Surgery

In most regions of Canada, and in some international centers, children are more likely to undergo surgery on a day surgery rather than inpatient basis (Newell, 1989; While & Crawford, 1992; Robinson & Elliot, 1993). As a result, children are sent home to be cared for by a parent within hours of day surgery. This means that the responsibility of providing postoperative care, including pain management, has been given to parents. Despite this shift in postoperative care, little is known about children's recovery from day surgery, and parents' management of it.

Recent reports indicate that children experience pain up to 48 hours after day surgery (Finley, McGrath, Forward, McNeill & Fitzgerald, 1996), and that parents administer inadequate amounts of analgesics (Gedaly-Duff & Ziebarth, 1994; Finley et al., 1996). Unfortunately, there were limitations to these investigations. For example, parent ratings of the child's pain were obtained rather than the more valid child ratings. In one study, the sampling plan resulted in small numbers per surgical category thus limiting analyses (Finley et al., 1996). Furthermore, follow-up ceased at 48 hours, a time when children were reported to have considerable pain.

The objectives of this study were to follow children and their parents for one week after day surgery to record children's postoperative pain and other outcomes, administration of analgesics, and, parent's views and concerns about providing postoperative care. Rather than choosing a diverse group of children and surgeries, tonsillectomy was selected as the target procedure since it is one of the operations most

commonly performed in day surgery, and it is known to result in postoperative pain (Finley et al., 1996).

Methods

Subjects and Setting

This study was conducted in all hospitals in the city providing pediatric day surgery for tonsillectomy. All children (5 - 16 years) having tonsillectomy day surgery were consecutively recruited during one four week period. Surgical procedures performed consisted of tonsillectomy alone or with adnoidectomy, and/or bilateral myringotomy. Inclusion criteria included consent of parents and children, and ability of children to use a visual analogue scale.

Instruments

Data were collected through face-to-face and telephone interviews. Instruments for data collection included a seven day medication log, a two part questionnaire, and a 100 mm visual analogue scale.

A daily medication log was designed for recording types of drugs, amounts, and times administered over the seven day follow-up period. The two part questionnaire was adapted from one previously pilot tested in this center on a sample of parents whose children were undergoing day surgery. Modifications made to the two part questionnaire, for this present study, were reviewed by an expert in questionnaire design and children's pain. Both open and closed items were included in the questionnaire to assess: (1) child's age, sex, general health status, and history of previous surgery; (2) recalled instructions provided by staff for postoperative

management; (3) progress of child's postoperative recovery; (4) perceptions of preparedness for the day surgery experience; and (5) expectations and concerns about pain.

A 100 mm visual analogue scale (VAS) was used for assessing pain intensity. The VAS is a sensitive, valid, reliable, and easily understood tool which has been used successfully with children aged 5 years and up (McGrath, de Veber & Hearn, 1985). The scale was arranged as a 100 mm vertical line anchored at the ends by the words, No Pain and Worst Pain Possible.

Children's comprehension and ability to use the VAS were assessed with an approach utilized in other research (Lander, Hodgins & Fowler-Kerry 1992). To demonstrate use of the VAS, children were first familiarized with the vertical VAS and then shown three faces from the pain scale of the Children's Anxiety and Pain Scale (Kuttner & Lepage, 1989). The faces were shown in a fixed, random order and the child was asked to rate the pain expressed by the faces. Correctly ranking the sketched faces indicated that the child was capable of using the VAS. All children participating in the study demonstrated ability to use the VAS.

Procedure

After admission to the day surgery unit but before surgery, children meeting study criteria and their parents were recruited. Participating children were instructed about and then skill assessed in using the VAS. Parents completed a questionnaire about their children's general health status and history of previous hospitalizations. Seven VAS scales (one for every day of the follow-up period) and a medication diary

were provided to parents. The use of the medication diary was demonstrated. While children were in the operating room, parents were asked to rate the amount of pain they expected their children to have the first evening of surgery. Approximately two hours after surgery, children were asked to rate their pain using the VAS. Their hospital charts were reviewed for the purposes of recording perioperative and postoperative analgesics that had been prescribed and administered.

Every day for seven days, parents were contacted by telephone in the early evening. Each phone call took approximately five to ten minutes. They were asked to report any issues or concerns encountered. Their children were brought to the telephone and re-instructed on use of the VAS. They were then asked, "How much pain do you have right now?" The children recorded their pain on the VAS and then placed the completed scale in an envelope that had been provided.

On the first and last day of follow-up, additional questions were posed to parents during the telephone interview. On the first day, parents were asked to describe any discharge instructions they received specific to postoperative pain management. On the last day, parents were asked to describe inconsistencies in information previously provided, and to describe any additional issues about providing postoperative care and pain management that were not previously asked. Suggestions for day surgery improvements were also recorded. At the end of the follow-up period, parents were asked to return the completed VAS scales and medication logs in a self addressed envelop that had been provided to them.

Results

Data Preparation

All data were coded and examined for completeness and accuracy. Distributions were inspected and descriptive statistics obtained for all variables. Pain was scored by measuring in millimeters the distance from the bottom of the VAS to the subjects mark. Mean pain ratings were then plotted across time. The total amount of analgesics each child received on a daily basis were then calculated. Because children received varying types and amounts of analgesics, daily analgesics for each child were first converted to IM morphine equivalents and then these amounts were divided by the respective child's weight in kilograms. The formulas used for conversion of acetaminophen and codeine to IM morphine equivalents come from a previous unpublished study conducted at this center by Dr. J. Lander (1993). The interview data obtained from the open ended questionnaire items were analyzed using content analysis. First, interview data were read several times to identify themes. Responses that were similar in description were color coded and grouped into 17 major categories. Frequency of common postoperative outcomes were then obtained.

Subject Characteristics

Apart from one child who was younger than the minimum age of five years, a total of 49 subjects were considered eligible. All were approached for study participation with the exception of one child who was taken to the operating room before the arrival of the researcher. Of those approached, two parents declined participation giving reasons such as lack of time and reluctance to have the child

involved in research. Therefore, 46 children were entered into the study. Nine children came from outside of the city, some traveling approximately 800 km. for the surgery.

Three children developed postoperative complications requiring admission to hospital. One, a five year old girl, was hospitalized on the first day following surgery for ear and throat infection. The other two lived in rural areas. Both were girls aged 16 and 5 years; and they were hospitalized at one and six days after surgery respectively. The sixteen year old girl was admitted for postoperative pain and throat infection, and the 5 year old for dehydration and hypoglycemia. Reasons for hospital admission were reported by the parents of these children.

The VAS scales were not returned by five families at the completion of the study (four boys and one girl, all residing in the urban center). The postoperative pain and analgesic administration data from these five families were not available for analysis. Also excluded from these analyses and the descriptive analysis of the interview data were the data from the two children who were hospitalized soon after day surgery. Data from the third child (admitted on the last follow-up day) was included in all analysis since the child was cared for by parents during the follow-up period and since no data were missing.

Therefore, 44 cases were used for content and descriptive analysis of the open and closed ended interview data, and 39 cases were used for analysis of pain ratings and analgesic administration. However, the number of cases used for analysis of the pain ratings and analgesic administration patterns varied between 33 and 39 cases since

data was missing on some variables. Only cases with complete longitudinal data were used for tests involving repeated measures ANOVA.

Table 1 presents descriptive statistics about the characteristics of the sample for each of the three groups (Study Completed, Readmitted, and Data Not Returned). Statistical comparisons of groups could not be undertaken because of small numbers in two groups.

Trajectory of Postoperative Pain

Children were followed for a period of seven days commencing the day of their surgery. The first day and evening of surgery is referred to as Day 1 with follow-up continuing until the last day of follow-up (Day 7). A repeated measures ANOVA was used to assess changes in postoperative pain over the seven days ($F = 32.06$, $df = 6$, $p < .0001$, $n=38$). Helmert contrasts were used to assess on what days significant time differences in pain ratings occurred. This test compares the pain rating for each postoperative day with the average pain rating of all days that follow. The comparison test (Helmert, $p = 0.05$) determined that pain intensity was significantly higher on evenings 1, 2, and 4 compared to other evenings. Mean daily ratings of postoperative pain intensity ranged from 71.0 (Day 1: $SD = 29.0$) to 25.1 (Day 7: $SD = 29.1$). Mean pain ratings are presented in Figure 1.

Pearson correlations were computed between parents expected level of pain for the evening on the day of surgery and the child's reported pain on that same evening. A significant, but modest positive correlation was found $r = .31$ ($p = .05$, $n=39$) indicating that high expected pain scores occurred with high child pain scores. Mean

pain rating by parents for Day 1 was 77.7 ($SD = 18.7$) compared to children's mean rating of 71.0 ($SD = 29.0$).

Prescribed and Administered Analgesics

Analgesics administered to the children were converted to IM morphine equivalents and daily means calculated. The day of surgery (Day 1) was not included in the analyses because it did not represent a 24 hour period of time as did the remaining 6 days. Mean daily milligrams of morphine (equivalents) ranged from 4.4 mg (Day 2: $SD = 4.1$) to 2.6 mg (Day 7: $SD = 3.7$). The mean amount of analgesics varied significantly over the 6 postoperative days analyzed ($F = 10.38$, $df = 5$, $p < .001$, $n = 35$). The amount administered was significantly higher on the second and third day after surgery compared to other days (Figure 2: Helmert, $p = 0.05$). The recommended therapeutic amounts of analgesics were also calculated on a milligram per kilogram basis and converted to IM Morphine equivalents/kg. These calculations were then compared with the amounts of analgesics actually administered to the children on Day 2. Out of 39 children, seven (18%) received more than the recommended therapeutic amount while 32 (82%) received less than the therapeutic amounts.

During the perioperative period, ten children received local infiltration of an anesthetic to the tonsil fossa in addition to a general anesthetic. Their pain during follow-up was compared with the other children who did not receive infiltration. The hypothesis of interest were the group main effect as well as the group x time interaction. ANOVA was used to compare the two groups (infiltration and no infiltration) over eight intervals (recovery room pain rating and seven daily pain

ratings). There were no significant differences for infiltration or no-infiltration group.

The group by time interaction was also not significant.

Of the 39 cases, 24 children (62%) were prescribed acetaminophen plain for postoperative pain, 11 (28%) were prescribed acetaminophen with codeine, and 4 (10%) prescribed codeine. Those prescribed acetaminophen with codeine were typically adolescents.

The maximum amount of analgesics that could be administered according to prescription, and the amount of analgesics that were actually administered were also compared. These comparisons were limited to the first 48 hours after surgery because most prescriptions were written PRN (as needed) and were not precise about when the regimen should be discontinued. Five children received what had been prescribed in the first 48 hours, and four received more than had been prescribed. The other 30 children (77%) received less than the prescribed amounts (Table 2).

The analgesic administration patterns during the night were examined for Day 1 and 2. Out of 39 cases, 14 children (36%) did not receive any night time analgesics during either of the two nights while 25 (64%) received night time analgesics on the first night of their surgery. Of these 25 children, 12 received analgesics on the first and second nights.

Pearson correlations were also done between mean daily pain scores and mean milligrams of Morphine (equivalents) administered for each of the seven days. While no significant correlations were evident on the second, third, fourth, and sixth postoperative day, a significant but modest positive correlation $r = .41$ ($p = .02$, $n = 34$)

was noted on Day 5. This indicates that high analgesic administration occurred with high children's pain scores.

Common Postoperative Occurrences

Each day, parents and children were specifically asked about the child's daily fluid and food intake, and they were asked to report the occurrences of certain negative postoperative outcomes the child may have experienced including occurrences of pain, nausea and vomiting, postoperative bleeding, fever, and sleep patterns. Other negative outcomes were also reported spontaneously. A total of 17 negative outcomes were reported for the 44 cases over seven days (Table 3). These included physiological outcomes such as throat and ear pain, and behavioral indicators such as irritability and refusing to cooperate. Parents may have reported these outcomes more than once.

Information regarding postoperative visits to a physician were also recorded for all 44 cases. Reasons for visits included unexpected intensity of pain, bleeding from the mouth, infection, and unexpected duration of convalescence.

Several open ended questionnaire items were used to obtain parent's perceptions about their care taking roles and any difficulties encountered. The 44 parents rated their level of worry in caring for their children low (Mean 5.0, SD 3.0), however, four parents stated they were concerned about hemorrhage or vomiting on the first evening after surgery. As follow-up proceeded, many parents increasingly described concerns about length of time for recovery, intensity and duration of postoperative pain, poor food and fluid intake, poor sleep patterns, and children's refusal to cooperate.

Although the 44 parents initially rated the preoperative information provided them as helpful for caretaking (Mean 7.6, SD 2.2), their later interview comments indicated practitioners did not provide comprehensive information about convalescence period, diet, fluid intake, pain trajectory, and pain management. Several parents also recommended that preoperative preparation for surgery be provided to children.

Discussion

On average, post-tonsillectomy pain followed a trajectory of intense or moderately intense pain for the first three days and this gradually declined to the level of mild pain over the next four days. Individual variations in this trajectory were observed. While several children reported little pain throughout the seven days, others appeared to suffer for the entire follow-up period. On the last day of follow-up, 8 children out of 39 (21%), reported pain above 50 mm on a 100 mm VAS. Of these 8, 3 children (8%) rated their pain above 50 mm on a 100 mm VAS for the entire seven days.

Pain trajectories did not differ for children who received an infiltration of a local anesthetic to the tonsil fossa compared to children who did not receive a local anesthetic perioperatively. The lack of difference may have been due to the small number who received a local infiltration, or because the local anesthetic the children received (bupivacaine) has an expected maximum benefit of only 6-8 hours.

Findings indicate that many parents experienced a difficult time during the post-operative period. Parents stated they lacked knowledge to aptly distinguish between normal and abnormal outcomes and they were not prepared for the length of time it

took their children to recover from surgery. This caused problems particularly for single parents, as they had to take extra time off work or ask other family members to care for their children.

Together, comments of parents, records of analgesic administration, and children's pain reports suggest that some aspects of health care are less than optimal for children having tonsillectomy in day surgery. Analgesic prescription and administration, as well as instruction of parents about postoperative care and pain management are two areas which contribute to problems with care.

To achieve satisfactory pharmacological pain management, three elements must be achieved: the correct drug must be prescribed, the dose must be correct, and it must be administered in an appropriate manner. The prescription is the responsibility of the physician and the administration the responsibility of the parent. Nurses and physicians are involved in the education of parents and children about drug administration.

Most children received acetaminophen plain postoperatively, and a few received acetaminophen with codeine. Because acetaminophen is the drug of choice for mild pain (Wilton, 1995), it was insufficient for the severe pain experienced by most children following tonsillectomy. Combining acetaminophen with codeine offers a stronger analgesic (Wilton), but one that is not capable of eliminating the severe pain experienced early after surgery. Larger sample sizes are required to longitudinally compare groups receiving different analgesic treatments on reported pain.

An additional problem was that many analgesic prescriptions did not meet the recommended therapeutic dose. These results are in agreement with findings reported

by Tesler, Wilke, Holzemer, and Savedra (1994). On some occasions where analgesics were prescribed at inadequate doses for children in this study, nurses in the day surgery intervened and advised parents to give more than the prescribed amount.

Some parents who had received an inadequate prescription took it upon themselves to administer more frequent doses of the prescribed analgesic, or to obtain alternative prescriptions from family physicians. In general, however, amounts of analgesics administered by parents were insufficient. This conclusion arises from the observation that many children experienced pain and many received fewer analgesics than their prescription would permit.

In this study, all analgesics were prescribed on a PRN basis rather than at regular intervals. Irregular analgesic administration is a major factor in poor pain control since it causes cycles of severe pain (Twycross, 1984; Yaster, Sola, Pegoli & Paidas, 1994). Administering a drug on a PRN basis gives responsibility to parents to determine if the child's pain warrants an analgesic.

Previous pain studies have relied on parental ratings of their children's pain. In this study, children as young as five demonstrated consistent ability to rate their own pain over a seven day period. These children were also able to successfully rate their pain over the telephone. Unfortunately in this study, most parents were not very skilled at estimating children's pain as determined by the rather modest positive correlation between a parent's expected pain and the child's report of pain.

The lack of significant correlation between children's mean pain scores and mean daily analgesic administration on the second, third, fourth and sixth day of

follow-up also indicates that no relationship exists between pain scores and analgesic administration. However, a significant but modest positive correlation was noted on Day 5. This finding may suggest that, on Day 5, children received more analgesics in reaction to increased pain intensity for unexpected ear pain. Parents may have been more responsive to change in kind, location or intensity of pain.

It appears that parents and their children have not been appropriately instructed about analgesic administration. It may be that parents require very detailed and specific instruction about analgesic administration and other related issues such as food and fluid intake. As well parents require instruction about assessment and prevention of complications such as infection, dehydration and hypoglycemia.

Parents were initially of the view that they had been given satisfactory information about their child's surgery and care. Most parents (58%) altered their views by the end of the follow-up period, after they had completed the experience of surgery and postoperative care.

In this sample, about twenty percent of parents did not know what to do when their children refused medication, fluids, or food. They finally resorted to asking the interviewer to speak with their children about the importance of food and fluid intake. Another parent telephoned during the night to talk about the hospitalization of her child for hypoglycemia and dehydration. This child had not received adequate amounts of fluid and food to prevent complications.

The number of visits to physicians on Day 5 may have been related to poor instruction of parents. Parents may not have been informed of the possible occurrence

of ear pain after tonsillectomy which occurred about Day 5. One set of instructions provided to some parents mentioned ear pain as a possible outcome, but no details were provided. Underestimation of parent information needs has been reported elsewhere (While & Wilcox, 1994).

Providing relevant information at various times, and utilizing innovative communication mediums may increase access to required information. These may include early mail out packages, or the use of interactive videos and computer on-line. Information about tonsillectomy, food lists, how to prepare children for the surgical experience, and how to deal with common postoperative outcomes may be included. On the day of surgery, a step by step instruction guide may be developed in collaboration with parents and children. The guide could assist parents with assessment of pain and other postoperative outcomes and analgesic administration. Postoperative telephone calls may be used to reinforce information and to provide additional guidance and support for families. Such personal contacts provide opportunities for parents and children to discuss their own situations. Children also need information, and they need to be given a role in assisting with their own care.

While this descriptive study uncovered important issues about children's recovery from tonsillectomy day surgery, obtaining larger sample sizes would extend findings by permitting group comparisons on demographic and other variables. As well, obtaining information about parental employment status and extent of perceived social support may also add to knowledge about parental caretaking. Replication of the study is also recommended as it would serve to strengthen study conclusions.

The findings discussed in this paper have implications for all health care professionals involved in the preoperative, perioperative, and postoperative preparation and care of the child having day surgery. Providing children and parents with necessary resources and knowledge may help parents to assume their care taking roles with confidence, reduce the occurrence of children's postoperative pain, reduce the length of surgical convalescence, and reduce family stress. These are essential if there is to be efficient day surgery involving children.

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Table 1
Characteristics of Sample

Variable	Completed Study n=38	Rehospitalized n=3	Did Not Return VAS n=5
Frequencies			
Gender			
Boys	17 (44.7%)	0	4
Girls	21 (55.2%)	3	1
Past hospitalization			
None	16 (42.1%)	1	1
Once	11 (28.9%)		3
More than once	11 (28.9%)	2	1
Previous surgery			
None	26 (68.4%)	1	2
Once	6 (15.8%)		3
More than once	6 (15.8%)	2	
Residence			
Urban	31 (81.5%)	2	0
Rural	7 (18.4%)	1	5
Surgical procedure			
Tonsillectomy & adnioidectomy	24 (63.1%)	1	4
Tonsillectomy	11 (28.9%)	1	1
Bilateral myringotomy, adnoideotomy & tonsillectomy	2 (5.2%)	1	
Myringotomy, adnoideotomy & tonsilectomy	1 (2.6%)		
General health status			
Excellent	10 (26.2%)	1	2
Very good	17 (44.7%)	2	1
Good	10 (26.2%)		1
Frequent illnesses	1 (2.6%)		1
New experience for parent			
No	16 (42.1%)	1	2
Yes	22 (57.9%)	2	3
Means			
Age in years (SD)	9.5 (3.5)	8.7 (6.5)	8.4 (3.1)

Figure 1: Mean Pain Ratings Over Seven Days

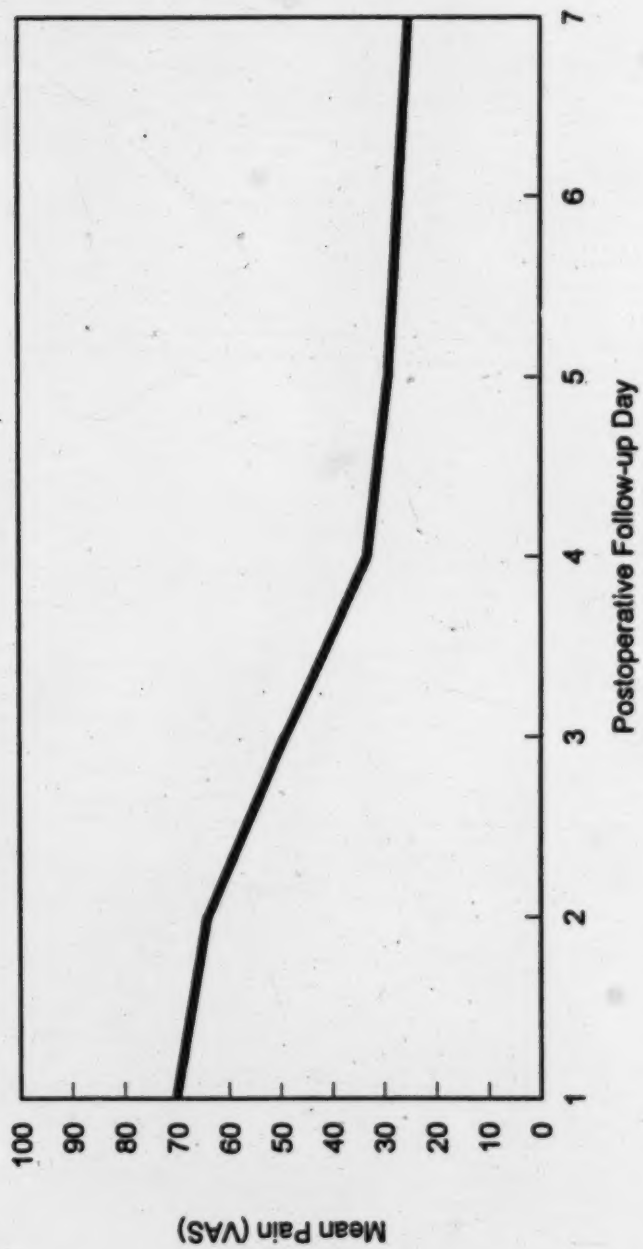


Figure 2: Mean Analgesic Intake Over Seven Days (in morphine meq)

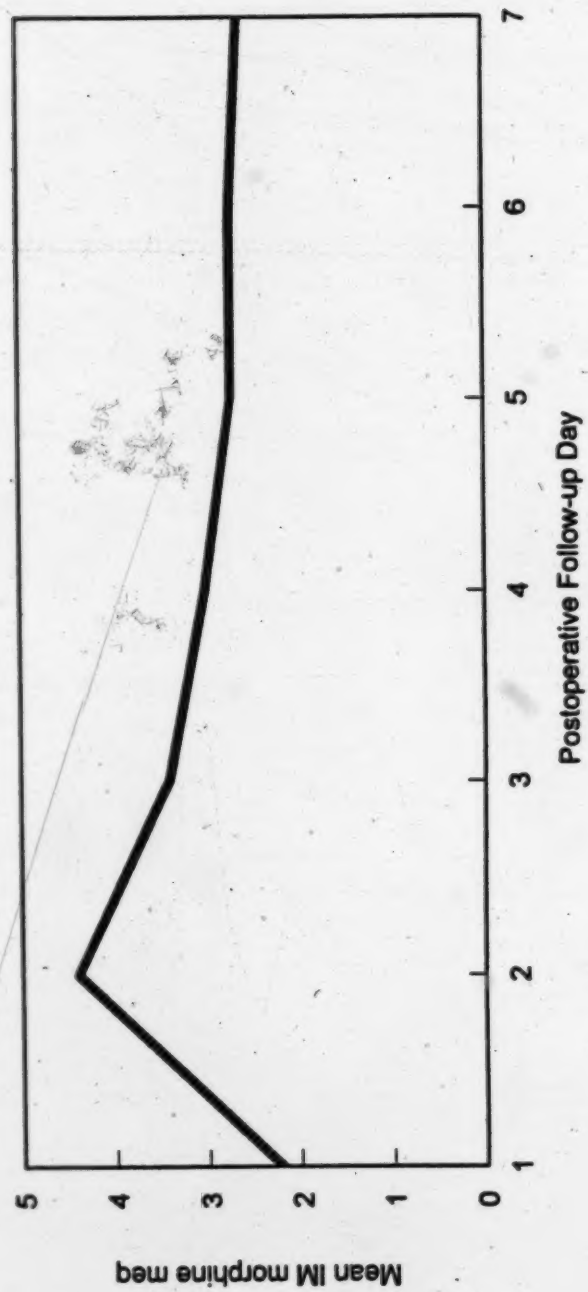


Table 2

Analgesic Administration Compared with Amount Prescribed

Amount of Analgesics Administered	Frequency
First 48 hours	
1. Received as prescribed n=5	5
2. Received % of prescribed n=30	
10-19%	0
20-29%	4
30-39%	2
40-49%	3
50-59%	2
60-69%	6
70-79%	6
80-89%	4
90-99%	3
3. Received % more than prescribed n=4	
100% + 10%	2
100% + 20%	1
100% + 50%	1

Note: n=39

Table 3

Common Postoperative Occurrences First Seven Days

Occurrence	% of Responses
Pain - throat	26.9
ears	13.0
neck, jaw, chest	2.3
Nausea	6.5
Vomiting	4.0
Fever	5.8
Sleepy, drowsy	5.0
Bleeding	1.2
Irritability	3.0
Fearful	3.0
Poor fluid intake	11.3
Medication not effective	1.8
Up during night (up crying)	7.6
Poor food intake	6.3
Infection (throat, ears)	.3
Congestion (nose)	1.2
Refusing medication	.8

Note: n = 44

Appendix A: List of Tables

Table A1

Mean Scores for Pain Intensity First Seven Days

Time	Mean	SD	p	n
During Hospitalization:				
Parental Pain Ratings	77.7	18.7		39
Child Pain Ratings (recovery room)	70.4	30.2		33
After Hospitalization:				
Child Pain Ratings: Day 1	71.0	29.0	.0001*	38
Day 2	64.0	23.5	.002*	38
Day 3	49.0	27.0		38
Day 4	33.0	24.0	.046*	38
Day 5	29.0	26.0		38
Day 6	27.0	25.0		38
Day 7	25.1	29.1		38

Note: * $p < .05$ (Helmert, $p=0.05$)

Table A2

Analysis of Variance: Pain Intensity Over Seven Days

	df	ms	F	P
Within & Residual	222	423.8		
Time	6	13586.86	32.06	.0001

Note n=38

Table A3

Analgesic Intake (IM Morphine Equivalents) First Seven Days

Time		Mean	SD	p
Day	2	4.4	4.1	.000*
	3	3.4	3.5	.003*
	4	3.0	4.1	
	5	2.7	3.9	
	6	2.7	3.8	
	7	2.6	3.7	

Note. N=35, * $p < .05$ (Helmert, $p = .05$)

Table A4

Analysis of Variance: Analgesic Intake (IM Morphine Equivalents) Over Six Days

	df	ms	F	P
Within & Residual	170	.00		
Time	5	.01	10.38	.000

Note: n=35

Table A5

Night Time Analgesic Administration Over 48 hours (Day 1-2)

<u>Administered during night</u>	<u>Frequency</u>
none	14
Day 1 (over 1st 24 hours)	25
Day 1 and 2 (over 1st 48 hours)	12

Note: n=39

Table A6

Types of Analgesics Prescribed

Time	Frequency (%)
Perioperatively	
Local anesthetic to tonsil fossa	10 (26%)
Acetaminophen suppository	2 (5%)
After Hospitalization	
Acetaminophen Plain	24 (62%)
Acetaminophen with Codeine	11 (28%)
Codeine	4 (10%)

Note: n=39

Table A7

Visits To Physicians

Variable	Frequency
Number of visits	
none	26
one	10
more than 1	5
Type of visit	
emergency department	7
medical clinic/family physician	6
surgeon	2
Day of visit	
Day 2	2
Day 3	1
Day 4	2
Day 5	6
Day 6	3
Day 7	1

Note: n=44

Table A8

Parental Perceptions for Caretaking

Responses to questionnaire items	Mean	SD
Items asked on evening of surgery		
Found information for caretaking helpful [1 is not very helpful - 10 is extremely helpful]	7.6	2.2
Worried in caring for child at home [1 is not worried - 10 is extremely worried]	5.0	3.0
Items asked on seventh day of surgery		
Prepared for caretaking role [1 is completely unprepared - 10 is totally prepared]	6.5	2.5

Note: n = 45

Table A9

Analysis of Variance: Gender and Pain Intensity Over Seven Days

	df	ms	F	P
<u>Between Subject Effects</u>				
Within & Residual	36	2288.5		
Gender	1	1216.4	.53	.471
<u>Within Subject Effects</u>				
Within & Residual	216	430.1		
Time	6	13406.7	31.17	.0001
Gender x Time	6	120.2	.28	.946

Table A10: Daily Analgesic Administration With VAS Ratings

Case	Wt/kg	Analgesic Prescribed	Recommended Therapeutic dose mg/kg	Day 1			Day 2			Day 3		
				Analgesics admin.	VAS Rating	Analgesics admin.	Analgesics admin.	VAS Rating	Analgesics admin.	VAS Rating	Analgesics admin.	VAS Rating
1	22.27	Tylenol 320mg q4h PRN	0.13	0.04	0	0.10	0.10	1	0.02	1	0.02	1
2	25.90	Tylenol 320 mg q4h PRN	0.12	0.03	38	0.07	0.07	51	0.05	58	0.05	58
3	66.81	Tylenol #2 1-2 tabs q4h PRN	0.14	0.00	90	0.06	0.06	89	0.03	78	0.03	78
4	21.36	Tylenol 300mg q4h PRN	0.12	0.06	100	0.09	0.09	52	0.11	56	0.11	56
5	24.77	Tylenol 300mg q4h PRN	0.12	0.05	1	0.13	0.13	2	0.14	52	0.14	52
6	22.27	Tylenol 300mg q4h PRN	0.12	0.02	100	0.06	0.06	59	0.04	87	0.04	87
7	45.45	Tylenol 600mg q4h PRN	0.12	0.03	68	0.10	0.10	55	0.08	43	0.08	43
8	47.72	Tylenol #3, 1-2 tabs q4h PRN	0.33	0.04	86	0.16	0.16	88	0.08	82	0.08	82
9	45.45	Codeine 25mg q3-4h PRN	0.15	0.06	91	0.13	0.13	93	0.02	67	0.02	67
10	24.00	Tylenol 240mg q4h PRN	0.13	0.02	64	0.07	0.07	85	0.06	93	0.06	93
11	23.00	Tylenol 240mg q4h PRN	0.12	0.04	40	0.10	0.10	47	0.04	31	0.04	31
12	21.20	Tylenol 300mg q4h PRN	0.12	0.04	90	0.13	0.13	50	0.04	0	0.04	0
13	78.50	Tylenol #2, 1-2 tabs q4h PRN	0.12	0.06	43	0.18	0.18	24	0.12	14	0.12	14
14	50.40	Tylenol #2, 1-2 tabs q4h PRN	0.19	0.08	69	0.24	0.24	64	0.29	69	0.29	69
15	22.60	Codeine 15mg q4-6h PRN	0.15	0.02	40	0.10	0.10	49	0.06	34	0.06	34
16	54.40	Codeine 15-30mg q4h PRN	0.16	0.03	95	0.12	0.12	91	0.07	73	0.07	73
17	58.00	Tylenol #2, 1-2 tabs q4h PRN	0.17	0.02	87	0.06	0.06	52	0.04	34	0.04	34
18	60.50	Tylenol #2, 1-2 tabs q4h PRN	0.16	0.07	91	0.10	0.10	84	0.10	75	0.10	75
21	31.00	Tylenol 465mg q4h PRN	0.12	0.03	74	0.08	0.08	85	0.00	23	0.00	23
23	21.00	Tylenol 240mg q4h PRN	0.12	0.04	5	0.10	0.10	99	0.08	7	0.08	7
24	22.20	Tylenol 300mg q4h PRN	0.12	0.03	100	0.08	0.08	63	0.05	43	0.05	43
26	42.50	Tylenol 300mg q4h PRN	0.12	0.02	95	0.10	0.10	97	0.02	75	0.02	75
27	21.50	Tylenol 300mg q4h PRN	0.12	0.07	98	0.10	0.10	54	0.04	23	0.04	23
28	24.00	Tylenol 360mg q4h PRN	0.13	0.06	96	0.09	0.09	74	0.09	92	0.09	92
29	23.70	Tylenol 300mg q4h PRN	0.12	0.04	94	0.11	0.11	51	0.08	50	0.08	50
30	23.60	Tylenol 350mg q4h PRN	0.12	0.02	89	0.08	0.08	88	0.05	75	0.05	75
32	20.00	Tylenol 300mg q4h PRN	0.12	0.12	49	0.35	0.35	40	0.16	48	0.16	48
33	41.30	Tylenol #2, 1-2 tabs q4-6h PR	0.23	0.35	83	0.22	0.22	92	0.17	70	0.17	70
34	45.20	Tylenol #3, 1-2 tabs q4-6h PR	0.35	0.06	37	0.04	0.04	32	0.04	12	0.04	12
35	43.00	Tylenol 320mg q4h PRN	0.12	0.06	9	0.20	0.20	62	0.20	35	0.20	35
38	70.00	Tylenol #3, 1-2 tabs q4h PRN	0.22	0.14	75	0.01	0.01	76	0.03	31	0.03	31
39	34.00	Tylenol 450mg q4h PRN	0.12	0.04	92	0.07	0.07	69	0.07	69	0.07	69
40	56.30	Tylenol #2, 1-2 tabs q4h PRN	0.17	0.04	96	0.03	0.03	54	0.05	54	0.05	54
41	78.75	Tylenol #3, 1-2 tabs q4h PRN	0.20	0.02	100	0.18	0.18	96	0.09	68	0.09	68
42	37.00	Codeine 15-30mg q4h PRN	0.15	0.06	82	0.07	0.07	68	0.11	50	0.11	50
43	65.40	Tylenol 650mg q4h PRN	0.12	0.07	52	0.07	0.07	66	0.11	14	0.11	14
44	20.00	Tylenol 240-360mg q3-4h PRN	0.13	0.06	56	0.04	0.04	15	0.04	18	0.04	18
45	34.10	Tylenol 325-600mg q4h PRN	0.12	0.04	46	0.04	0.04	55	0.04	43	0.04	43
46	31.20	Tylenol 360-600mg q4h PRN	0.12	0.04								

Note: * denotes missing data. All analgesics for all days are in IM morphine equivalents (morphine mg /kg), n = 39

Table A10: Daily Analgesic Administration With VAS Ratings

Case	Wght/kg	Day 4			Day 5			Day 6			Day 7		
		Analgesics admin.	VAS Rating	Analgesics admin.	VAS Rating	Analgesics admin.	VAS Rating	Analgesics admin.	VAS Rating	Analgesics admin.	VAS Rating	Analgesics admin.	VAS Rating
1	22.27	0.00	1	0.02	1	0.00	1	0.00	1	0.04	1	0.04	1
2	25.90	0.00	20	0.00	0	0.00	0	0.02	33	0.00	70	0.00	70
3	66.81	0.00	55	0.06	21	0.03	28	0.12	28	0.16	5	0.16	5
4	21.36	0.00	26	0.03	9	0.14	50	0.09	54	0.02	*	0.02	*
5	24.77	0.14	50	0.02	8	0.08	8	0.04	9	0.06	37	0.06	37
6	22.27	0.06	29	0.08	8	0.04	69	0.09	84	0.08	26	0.08	26
7	45.45	0.08	27	0.04	69	0.12	63	0.01	53	0.01	53	0.01	53
8	47.72	0.04	72	0.07	40	0.04	0	0.04	0	0.04	5	0.04	5
9	45.45	0.04	60	0.04	45	0.00	19	0.00	10	0.00	6	0.00	6
10	24.00	0.06	80	0.00	19	0.02	0	0.02	13	0.05	0	0.05	0
11	23.00	0.00	21	0.06	11	0.33	56	0.26	68	0.29	31	0.29	31
12	21.20	0.00	0	0.00	11	0.00	11	0.00	4	0.00	0	0.00	0
13	78.50	0.12	15	0.07	35	0.05	7	0.05	7	0.05	7	0.05	7
14	50.40	0.29	56	0.02	19	0.04	35	0.04	35	0.04	28	0.04	28
15	22.60	0.02	16	0.02	58	0.03	34	0.03	28	0.05	28	0.05	28
16	54.40	0.06	37	0.00	58	0.00	80	0.00	8	0.00	8	0.00	8
17	58.00	0.05	14	0.06	54	0.05	5	0.05	5	0.03	5	0.03	5
18	60.50	0.11	73	0.02	15	0.08	15	0.08	57	0.04	60	0.04	60
21	31.00	0.00	54	0.08	20	0.05	3	0.05	3	0.01	2	0.01	2
23	21.00	0.06	7	0.04	20	0.00	3	0.00	20	0.00	0	0.00	0
24	22.20	0.06	10	0.05	18	0.07	14	0.07	14	0.14	98	0.14	98
26	42.50	0.01	1	0.00	13	0.02	6	0.02	6	0.02	8	0.02	8
27	21.50	0.00	1	0.02	20	0.02	15	0.02	15	0.00	0	0.00	0
28	24.00	0.02	25	0.05	95	0.04	10	0.04	10	0.07	8	0.07	8
29	23.70	0.02	73	0.02	21	0.03	19	0.03	52	0.03	30	0.03	30
30	23.60	0.02	22	0.05	19	0.30	2	0.35	14	0.26	9	0.26	9
32	20.00	0.07	85	0.03	3	0.02	2	0.02	2	0.01	2	0.01	2
33	41.30	0.05	38	0.14	9	0.03	38	0.14	38	0.20	59	0.20	59
34	45.20	0.22	37	0.00	2	0.05	0	0.03	0	0.01	0	0.01	0
35	43.00	0.03	4	0.05	45	0.07	20	0.07	20	0.08	14	0.08	14
38	70.00	0.22	20	0.05	73	0.04	53	0.04	53	0.03	26	0.03	26
39	34.00	0.01	17	0.12	99	0.09	51	0.09	99	0.09	99	0.09	99
40	56.30	0.05	22	0.10	49	0.17	54	0.17	54	0.12	34	0.12	34
41	78.75	0.05	31	0.00	2	0.00	0	0.00	0	0.03	3	0.03	3
42	37.00	0.15	62	0.04	7	0.04	2	0.04	2	0.04	0	0.04	0
43	65.40	0.14	43	0.04	40	0.04	40	0.04	36	0.04	23	0.04	23
44	20.00	0.11	47	0.04	40	0.04	40	0.04	36	0.04	23	0.04	23
45	34.10	0.04	6	0.04	40	0.04	40	0.04	36	0.04	23	0.04	23
46	31.20	0.04	40	0.04	40	0.04	40	0.04	36	0.04	23	0.04	23

Note: * denotes missing data. All analgesics for all days are in IM morphine equivalents (morphine mg /kg), n = 39

Appendix B: Examples of Data Collection Tools

Data Collection Form

Case #	child name (age, sex.), parent name	Type of surgery	Wght in kg	phone (hotel/home)	VAS (pract/rr)	peri-op analgesic/ local anesthetic	discharge analgesic prescription

CASE _____

NAME _____ 6

Visual Analogue Scale

Draw a mark through the line to show how much it
hurts

Worst Pain Possible



No Pain

QUESTIONNAIRE 1: BEFORE SURGERY

1/Case _____

These questions will give us a better picture of the parents and children who are taking part in this study.

1. How would you rate (X's) general health? Is it excellent, very good, good or does (X) have frequent illness?

__ EXCELLENT __ VERY GOOD __ GOOD __ FREQUENT ILLNESS

What kind of health problem(s) does (X) have?

2. Is this the first time (X) has had surgery?

__ YES

__ NO



How many times has (X) had surgery? __ TIMES

What were the reason(s) for the other surgeries?

3. Is this the first time (X) has been in hospital?

__ YES

__ NO



How many time has (X) been in hospital? ____

What were the reason(s) for other hospitalizations?

2/CASE ____

4. Is the experience of having a child in day surgery a new one for you or not?

__ YES

__ NO

5. Suppose that all pain can be represented on a line. At one end of the line is no pain at all and at the other end of the line is the worst pain imaginable. The amount of pain that any person has can lie anywhere along the line.

Mark an X on the line to indicate how much pain you expect your child to have the first evening after the operation.

No
pain

_____ worst pain
imaginable

1/CASE ____

Date: _____

**QUESTIONNAIRE 2(1):
AFTER SURGERY - BY PHONE :**

Name of Informant [child] _____ [parent] _____]

Parent Interview:

I will begin by reminding you that any information you provide is confidential. The researcher is separate from the hospital and your doctor. This independent investigation will help us to understand how often and how much children have certain discomforts following their daysurgery. Your frank views are valued.

Today, I will first speak with you and then I will speak with (X) if they are awake. This phone call will take about 10 minutes.

If (X) is asleep, I will ask you to give me the time (X) rated their pain this evening.

If (X) is awake, I will ask (X) to use the ruler to tell me about any pain he/she is having now. It is important that (X) gives me their own rating. You may help (X) during this time if necessary. It is also important that the ruler they complete be put in the envelop.

Before we begin, I would like to arrange a time for me to call you tomorrow between 5 and 7 pm. What time is the most convenient for you? _____. Thank you.

1. I will begin by asking you how things are going so far for you ... in caring for (X)?

2. How are things going for (X) ... so far?

Thinking back to the types of preparation (information) you received from doctors, nurses or any other staff about how to care for (X) after the operation.

2/CASE ____ CHILD'S NAME _____

3. What did doctors, nurses, or other staff tell you about pain after an operation?
4. What did doctors, nurses, or other staff tell you about how to care for (X) after his/her operation?
5. What information did doctors, nurses, or other staff give you about caring for (X)'s pain at home?
6. On a scale of 1 to 10, where 1 is not very helpful and 10 is extremely helpful ...

How helpful has the information been so far?

1 2 3 4 5 6 7 8 9 10

Just one more question...

7. Some people are worried about being able to care for a child at home after day surgery and others are not. On a scale of 1 to 10 where 1 is not worried and 10 is extremely worried.

How worried did you feel is caring for (X) at home after day surgery? (if over 7 probe)

1 2 3 4 5 6 7 8 9 10

3/CASE ____ CHILD'S NAME _____

I wish now to record the time for today's pain rating. Is (X) asleep?

If child NOT asleep proceed with the following

Child Interview repeat this for every phone call during the 7 day follow-up period):

Hello, I am Fay Warnock.

I am the nurse who spoke with you and your mom at the hospital.

I showed you how to the scale. Remember?

The scale will help you to tell me how much "pain" you have now.

Now look at the paper with the line on it.

Is your name at the top of the page?

Is the number 1, 2, 3, 4, 5, 6, 7 on top of the page?

Remember that "no pain" is at the very bottom of the line and the "worst pain possible" is at the top of the line.

Now thinking about the pain you have now, draw a mark through the line to show how much you hurt.

Now, please put the ruler you just marked in the envelop Thanks (X)! I will call you again tomorrow.

If child asleep ask the following

Please tell me the time (X) rated his/her pain today using the ruler marked #1 on the top right hand side? Thank you.

8. Time of child's rating of pain _____

4/CASE ____

Date: _____

**QUESTIONNAIRE 2(2):
AFTER SURGERY - BY PHONE :**

Name of Informant [child] _____ [parent] _____]

Parent Interview:

I will begin by reminding you that any information you provide during the duration of this study is confidential. The researcher is separate from the hospital and your doctor. This independent investigation will help us to understand how often and how much children have certain discomforts following their daysurgery. Your frank views are valued.

Today, and for the next 5 days, I will ask you two questions and then I will speak with (X). I will then ask (X) to use the ruler to tell me about any pain he/she is having. You may help (X) during this time if necessary. It is also important that the ruler they complete be put in the envelop. This phone call will take about 5 minutes.

Before we begin, I would like to arrange a time for me to call you tomorrow between 5 and 7 pm. What time is the most convenient for you? _____. Thank you.

9. I will begin by asking you how things are going so far for you ... in caring for (X)?

10. How are things going for (X) ... so far?

Thank you, I wish now to speak with (X).

Repeat VAS orientation.

11. Time of child's rating of pain _____

5/CASE _____

Date: _____

**QUESTIONNAIRE 2(2):
AFTER SURGERY - BY PHONE :**

Name of Informant [child] _____ [parent] _____]

As we discussed yesterday, I will ask you two questions and then I will speak with (X). I will ask (X) to use the ruler to tell me about any pain he/she is having. This phone call will take about 5 minutes.

Before we begin, I would like to arrange a time for me to call you tomorrow between 5 and 7 pm. What time is the most convenient for you? _____. Thank you.

12. I will begin by asking you how things are going so far for you in caring for (X)?

13. How are things going for (X) so far?

Thank you, I wish now to speak with (X).

Repeat VAS orientation.

14. Time of child's rating of pain _____

6/CASE ____

Date: _____

**QUESTIONNAIRE 2(4):
AFTER SURGERY - BY PHONE :**

Name of Informant [child] _____ [parent] _____]

Parent Interview:

I will begin by reminding you that any information you provide is confidential. Today, I will again ask you the same two questions I asked you yesterday and then I will speak with (X). I will again ask (X) to use the ruler to tell me about any pain he/she is having. This phone call will take about 5 to 10 minutes.

Before we begin, I would like to arrange a time for me to call you tomorrow between 5 and 7 pm. What time is the most convenient for you? _____. Thank you.

15. I will begin by asking you how things are going so far for you in caring for (X)?

16. How are things going for (X) so far?

Thank you, I wish now to speak with (X).

Repeat VAS orientation.

17. Time of child's rating of pain _____

7/CASE ____

Date: _____

QUESTIONNAIRE 2(5):
AFTER SURGERY - BY PHONE :

Name of Informant [child] _____ [parent] _____]

Parent Interview:

I will again ask you the two questions and then I will speak with (X). I will ask (X) to use the ruler to tell me about any pain he/she is having. Again this phone call will take about 5 minutes.

Before we begin, I would like to arrange a time for me to call you tomorrow between 5 and 7 pm. What time is the most convenient for you? _____. Thank you.

18. I will begin by asking you how things are going so far for you in caring for (X)?

19. How are things going for (X) so far?

Thank you, I wish now to speak with (X).

Repeat VAS orientation.

20. Time of child's rating of pain _____

8/CASE _____

Date: _____

QUESTIONNAIRE 2(6):
AFTER SURGERY - BY PHONE :

Name of Informant [child] _____ [parent] _____]

Parent Interview:

Today, I will again ask you the two questions and then I will speak with (X). I will ask (X) to use the ruler to tell me about any pain he/she is having. This phone call will take about 5 minutes.

Before we begin, I would like to arrange a time for me to call you tomorrow between 5 and 7 pm. What time is the most convenient for you? _____. Thank you.

21. I will begin by asking you how things are going so far for you in caring for (X)?

22. How are things going for (X) so far?

Thank you, I wish now to speak with (X).

Repeat VAS orientation.

23. Time of child's rating of pain _____

9/CASE _____

Date: _____

QUESTIONNAIRE 2(7):
AFTER SURGERY - BY PHONE :

Name of Informant [child] _____ [parent] _____]

Parent Interview:

I will begin by reminding you that any information you provide is confidential.

Today, I will ask you the same two questions I asked you yesterday but today I will ask you to answer some additional questions. I will again ask (X) to use the ruler to tell me about any pain he/she is having now. This phone call will take about 10 minutes.

24. I will begin by asking you how things are going so far for you in caring for (X)?

25. How are things going for (X) so far?

26. Now, I would like to ask you a question about preparation for day surgery.

On a scale of 1 to 10 where 1 is completely unprepared and 10 is totally prepared

How prepared were you in caring for (X) at home after day surgery? (if under 7 probe)

1 2 3 4 5 6 7 8 9 10

10/CASE _____ CHILD'S NAME _____

27. At the start of the study, we asked you about information you received from doctors, nurses or other staff. Now, I would like to ask you to if you received any information from doctors, nurses, or other staff that you found to be inconsistent with (different from) what you have experienced at home in this past week?

As you can see from the questions we have asked, we are interested in understanding how long it takes children to recover from this operation and how children/teens and their parents deal with any aches, pains or problems after an operation.

28. Now I would like to ask you if there were any issues or problems about caring for children at home following day surgery which we did not ask you ... but which you feel are important.

Then thank them and say their assistance is appreciated. Ask them to enclose all of the completed pain rulers and the medication log in the envelop they were provided and mail it back as soon as they can. If they think of other issues that are important to consider over the next few days they can call the phone number on their consent form and leave a message. We will call them back.

Thank you, I wish now to speak with (X).

Repeat VAS orientation.

29. Time of child's rating of pain _____

LOG FOR RECORDING MEDICINE

Directions.

- Each time _____ takes medicine for pain, please write down the:
 name of the medicine
 amount of medicine given
 time medicine given
- Do this for the day of operation and for the next 6 days.
- Each day starts at 1 minute after midnight

- For example:
 Your son's surgery was on Wednesday, June 18. On this day, you gave your son:
 2 teaspoons of Tylenol at 2pm
 2 teaspoons at 6 pm
 2 teaspoons at 10pm

- You would record the medicine on your log sheet like this:

Day _____ Date _____

NAME of medicine	AMOUNT given	TIME given
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----

Day 1 _____ Date _____

NAME of medicine	AMOUNT given	TIME given
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----

Day 2 _____ Date _____

NAME of medicine	AMOUNT given	TIME given
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----
-----	-----	-----

Note: Log for recording daily analgesic administration continues until Day 7

ASSESSING OUTCOMES OF SHORT-STAY HOSPITALIZATIONS

Consent Form

OUR REASON FOR DOING THIS STUDY

To find out:

- how children or teenagers and their parents handle short-stay hospitalizations specific to postoperative pain
- strengths and gaps in programs for short-stay hospitalizations specific to postoperative pain management
- how long it takes for children teens to recover from an operation
- how children or teens and their parents deal with any aches, pains or problems after an operation

THE PEOPLE DOING THIS STUDY ARE:

- Fay Warnock, BScN, Nursing, University of Alberta
- Janice Lander, Phd, Nursing, University of Alberta

WHAT WILL HAPPEN IN THIS STUDY?

- we will ask you questions about:
 - how prepared you felt for your son's day surgery
 - your expectations and concerns about pain
 - your son's recovery from surgery
 - instructions you were given for your son's care after discharge
- we will show your son how to use a ruler to measure pain
- after his operation, we will help him to use this ruler to tell about any pain he has
- we will get information from your son's hospital chart about the kinds of pain drugs your son received in hospital
- we will ask that you keep a record of any pain drugs that your son takes during the week. This will take a few minutes each time you up-date the record
- one of us will telephone once each day for 7 days
 - we will ask your son to use the pain ruler to describes how he feels
 - this takes a few minutes each time
 - we will also ask you about how your son is doing
 - if our telephone call comes at a bad time, you just say so and we will call back later
- at the end of a week, we will ask you to mail your drug record and the pain rulers.
- we will give you an envelope with a stamp on it for mailing these papers to us.

WHAT WILL HAPPEN WITH THE INFORMATION?

- We will safely store it in a locked cupboard when not analyzing it. We will not put your name or your son's name on any study records. We will not name you or him in any articles or talks about this study.
- You do not have to be part of this study. Your son's care will not change whether you do or do not join the study. If you decide to join this study, you can decline to answer any of our questions. You can drop out of the study whenever you wish. Just tell the staff or us.

QUESTIONS?

- I am happy to answer any questions now. If you have questions later, call:
Janice Lander, PhD (403) 492-6317

I have read this information and agree to let my son _____

join this study, *Assessing Outcomes of Short-Stay Hospitalizations*

(signature of parent)

date

(signature of child/teen)

(file number)

Appendix C: Analgesic Conversion Table

Computations For Analgesic Conversion

Conversion to analgesic equivalent of morphine (IM):

Tylenol

Plain	1 tablet = 325 mg acetaminophen = .4500 mg IM morphine
	2 tablets = 650 mg acetaminophen = .9000 mg IM morphine
Extra Strength	1 tablet = 500 mg acetaminophen = .6900 mg IM morphine
Junior caps	4 caplets = 640 mg acetaminophen = .8861 mg IM morphine
Chewable	1 tablet = 80 mg acetaminophen = .1107 mg IM morphine

Elixir (Temptra)

1 tsp.	= 160 mg acetaminophen = .2215 mg IM morphine
1.5 tsp.	= 240 mg acetaminophen = .3322 mg IM morphine
2 tsp.	= 320 mg acetaminophen = .4430 mg IM morphine
2.5 tsp.	= 400 mg acetaminophen = .5537 mg IM morphine
3 tsp.	= 480 mg acetaminophen = .6645 mg IM morphine
3.5 tsp.	= 560 mg acetaminophen = .7752 mg IM morphine

Tylenol with Codeine Tablets:

Tylenol #1	1 tablet = 325 mg acetaminophen = .4500 mg IM morphine plus 8 mg codeine (oral) = .3750 mg IM morphine Therefore, 1 tylenol # 1 tablet = .825 mg IM morphine
Tylenol #2	1 tablet = 325 mg acetaminophen = .4500 mg IM morphine plus 15 mg codeine (oral) = .7500 mg IM morphine Therefore, 1 tylenol # 2 tablet = 1.20 mg IM morphine
Tylenol #3	1 tablet = 325 mg acetaminophen = .4500 mg IM morphine plus 30 mg codeine (oral) = 1.50 mg IM morphine Therefore, 1 tylenol # 3 tablet = 1.95 mg IM morphine

Tylenol with Codeine Elixir

1 tsp. (5 ml)	= 160 mg acetaminophen = .2215 mg IM morphine plus 8 mg codeine (oral) = .3750 mg IM morphine Therefore, 1 tsp. tylenol elixir = .5965 mg IM morphine
2 tsp. (10 ml)	= 1.193 mg IM morphine

Codeine Syrup

1 ml oral codeine	= 5 mg codeine	= .25 mg IM morphine
1.5	= 7 mg codeine	= .35 mg IM morphine
2	= 10 mg codeine	= .50 mg IM morphine
2.5	= 12 mg codeine	= .60 mg IM morphine
3	= 15 mg codeine	= .75 mg IM morphine
3.5	= 17 mg codeine	= .85 mg IM morphine
4	= 20 mg codeine	= 1.00 mg IM morphine
4.5	= 22 mg codeine	= 1.10 mg IM morphine
5	= 25 mg codeine	= 1.25 mg IM morphine
5.5	= 27 mg codeine	= 1.35 mg IM morphine
6 ml oral codeine	= 30 mg codeine	= 1.50 mg IM morphine

Recommended Therapeutic Dose

acetaminophen: 15 mg/kg q4-6hr

codeine: .5 - 1.0 mg/kg q4-6hr

Reference: Lander, J. (1993). [Children's appendectomy study]. Unpublished raw data.

Calculations for Table 10A (pg. 64, 65) (in IM morphine equivalents mg/kg)

Recommended therapeutic dose (RTD) for acetaminophen plain:

weight in kilograms x 15mg = M

M x 6 (# of doses/24hr) = N

N x .4500 (mg of IM morphine in 1 tab of tylenol plain) = P

P/325 (mg of acetaminophen in 1 tab of tylenol plain) = RTD

Recommended therapeutic dose for codeine:

weight in kilograms x .5mg = M

M x 6 (# of doses/24hr) = N

N x .25 (mg of IM morphine in 1 ml of codeine) = P

P/5 (mg of codeine in 1 ml of codeine) = RTD

Tylenol # 1: .825mg x 8 doses in one 24 hour period = N

Tylenol # 2: 1.20 mg x 8 doses in one 24 hour period = N

Tylenol # 3: 1.95 mg x 8 doses in one 24 hour period = N

Appendix D: Responses to Questionnaire Part 2

Day 1

1) How are things going so far for you ... in caring for (X)?

Day	Case	Parent Responses to Questionnaire Item
1	01	I am tired, didn't get home until 4 pm, ride home OK, X slept (<i>only child, single parent working full time</i>)
	02	good, child easy to care for, X taking it much easier than I thought, ride home ok (<i>mom accompanied by X's 9 year old sibling, live on acreage</i>)
	03	not too bad, I am tired, up since 5 AM, I am worried about X, things look good though
	04	I didn't expect X to be so sleepy for so long, I do try to give X Tylenol, X is in a great deal of pain when X is awake
	05	X is really good, quiet, playing, I am surprised X is not in as much pain as I thought X would be, it is not difficult to get X to drink
	06	I was up all night, I was worried sick, today as I see X, I am not worried as much. Doing better, seeing X makes me feel better I am scared X will throw up
	07	Its fine. Its been a long day, with 2 of them having day surgery (other child, adnoidectomy). X is doing better than I thought X would, ride home was tiring
	08	fine, just got home, (7:30 PM), long day
	09	X slept awhile, I was up last night, we all had early start today
	10	so far so good, X has been sleeping on and off

Day	Case	Parent Responses to Questionnaire Item
1	11	good, X has been great
	12	fine, I feel I got lots of good information, useful
	13	things are going well
	14	I'm tired, sitting in hospital from 8 am to 7 pm. A student nurse stuck X's IV and tried it again, student should not practice on child who is left alone. X has been complaining all day swollen hand, begged nurse to take it out, didn't take it out. So sick, if put in properly X wouldn't complain so much. Should practice on adults, should have told nurse to take a hike, didn't warn X or me, it isn't fair. Nurses made light of it until they believed X. not warranted on child.
	15	really good, long day, supportive husband and mother, relieved to have X at home
	16	long day, just got in (7:15 pm)
	17	little stressful, had a rough go with it, ok now
	18	not too bad, tough when hurting and can't help them, long day today
	19	I'm exhausted!, needed a few hours sleep, I'll be ok now
	20	ok (<i>mom sounds awful! coughing sneezing</i>)

Day	Case	Parent Responses to Questionnaire Item
1	21	ok
	22	good, X's brother was very cranky with his, seems like X didn't have OR
	23	fine, been a long time
	24	didn't get home until 4 pm, X was nauseated, vomited, no questions now, pleased with how X is.
	25	pretty good, home 2:30 - no questions now
	26	not too badly, concerned X keeps throwing up, would suppository work? Husband went to get Gravol suppository, other than that doing fine, don't have thermometer, don't have comforts of home (no right food, nothing). <i>(family out of town, in hotel for night)</i>
	27	<i>I was unable to contact family throughout follow-up period (mom and child stayed with child's grandparents), mom sent daily VAS's and medication sheets at end of follow-up period. Used written descriptive data that mom sent in later.</i>
	28	pretty good, gave X Gravol, X is grumpy, voice is the same -- wonder if they took out nodule?
	29	not bad, X has been good about it, difficult to force fluids, no questions -- if X gets warmer, ok to put in bathtub?
	30	not too bad, pretty tired, long day, got home 430 pm, no questions

Day	Case	Parent Responses to Questionnaire Item
1	31	X got worse when got home, prescription for Codeine not filled out properly by Dr., pharmacist didn't know what to do, we got in at 6 pm <i>(mom sounds tired)</i>
	32	pretty good, X is not asking for much, left hospital 4 pm, no questions
	33	going, gave me a sheet with discharge instructions on it, would have preferred this before X had OR, I am doing ok, home at 530, X was ready to go, was sleepy, leaned on me to car but was able to walk
	34	fine, don't have a problem, I think because of X's age it makes a difference, not as whinny as young person would be -- long day, X (child) felt like going home, no questions
	35	its not bad. But hard for taking medication - X cannot take Tylenol, doesn't like taste, telling X to take medicine at the scheduled time so it has great effect
	36	good
	37	ok, concerned about X vomiting, and X in a lot of pain
	38	pretty good, husband here for support, not uncomfortable with that, X is sore doing better than I thought X would
	39	fine, X feels bad, X feels so rotten, once tomorrow comes X will be ok
	40	long day, good, a little hard when throat hurts, I don't do much about it

Day	Case	Parent Responses to Questionnaire Item
1	41	unable to contact
	42	not too good, pretty hard for X to drink, hard to be in hotel
	43	quite well, went straight to bed, taking sips of fluid, getting along very well
	44	unable to contact
	45	long day, I'm tired
	46	<i>same as above</i>

Day 1

2). How are things going for (X) ... so far?

Day	Case	Parent/Child Responses to Questionnaire Item
1	01	Parent X drowsy, nauseated initially, wonderful, appetite jello and tea, taking lots of fluids Child (sleeping)
	02	Parent X has been awake whole time, swallowing ok, no vomiting, no complaints of pain Child (sleeping)
	03	Parent X not throwing up, taking ice chips, laying down, dozing on and off Child(sleeping)
	04	Parent when X is up X complains of pain, sleepy, never did have a wake up period, when try to wake X, X is irritable, had 1/3 cup water, ice chips and popsicle, no vomiting Child (sleeping)
	05	Parent X eating popsicles, drinking, has quiet time, sleeping now, X complained it hurts - took Tylenol, felt sick when home, I gave X an ice collar, X has fallen asleep a few times Child good, watching TV, playing
	06	Parent X is ok, complaining it is sore, had 1 cup jello Child (sleeping)
	07	Parent pain medication wearing off, needs more than what was prescribed, X is complaining of a lot of pain now, no vomiting Child fine, good, hard to swallow
	08	Parent fine until coming home, X vomited leaving hospital and on way home, managed to take fluids ok, feels dizzy when up"(mom thinks reason for vomiting is getting up with dizziness) Child (sleeping)
	09	Parent X drinking gingerale, ice water, had 2 bites of jello, no tummy ache, sleeping now. Child (sleeping), I was unable to speak with this child throughout the data collection period, arrangement made on first day as child very fearful
	10	Parent X doing fine, up and about, ate jello soup popsicles, no complaints, had bit of tummy ache, gas bothers X the most Child good, thing back there bothering me, hurts to swallow, drinking not too much

Day	Case	Parent/Child Responses to Questionnaire Item
1	11	Parent X doing well, talking, game playing, relaxing watching TV, had soup, popsicle, visit with grandma and neighborhood friends Child (sleeping)
	12	Parent X slept most of day, fine on top with the Tylenol (if we get handle on pain X will be happier) fluids, good intake, big water drinker, no tummy ache, no vomiting, no temp, perspired a lot during sleep Child (sleeping)
	13	Parent X resting, doing quite well, fluids, no fever now, no tummy ache, no vomiting at all Child (sleeping)
	14	Parent X kept throwing up, can't keep anything down, not doing well, nurses kept X in until now, gave us Tylenol suppository, in bed now sleeping, dizzy on

		way home, had 2 bottles IV, had popsicle and apple juice - threw them up, threw up old blood, X cried today a lot, is dizzy Child (sleeping)
	15	Parent X vomited a lot in hospital, awake now drinking fluids, no fever, slept other than up for medication Child (sleeping)
	16	Parent X good, vomited frequently in hospital, X got Demerol before leaving hospital, no fever now, taking sips of water Child (sleeping)
	17	Parent X vomited in hospital couple of times, gave X, IM Gravol, refused Gravol suppository, drinking slowed down, not eating, no tummy ache now, had terrible spasms, feels hot to touch Child (sleeping)
	18	Parent X good, throat sore, gas build up in car, home 8:15 pm, no vomiting in hospital, no vomiting at home yet, no fever, taking lot of fluids Child (sleeping)
	19	Parent X sore now, can't swallow anything, taking ice chips, ate jello, no tummy ache, no fever, no bleeding Child not too bad, hard to swallow
	20	Parent X sleeping now, throat sore, gave medication, drinking if encouraged, ate popsicles, pudding. vomited on way home, friend drove, no bleeding Child (sleeping)

Day	Case	Parent/Child Responses to Questionnaire Item
1	21	Parent we just got home, X didn't want to wake up in hospital, vomited ++. Gravol given, X slept from this, drinking sips, tried jello, on fever, no bleeding Child (sleeping)
	22	Parent X has been reasonably good, X has been sleeping since X got home, drinking, ice cream mashed potatoes, no vomiting, ears bothering X a bit, moaning in sleep Child (sleeping)
	23	Parent good, X wants to go out for a bike ride, no vomiting, no upset stomach, drinking approx. 1/3 cup/hr, drinking water, milk, ice cream popsicles, no bleeding Child good drinking ok, pain when swallow
	24	Parent pretty good, X had 1/3 cup juice with Tylenol, it wears off quickly, has throat pain, no vomiting Child (sleeping)
	25	Parent pretty well, X sleeping, not as tense, drank, ate jello, no vomiting, had upset stomach was nauseated on ride home, now ok, up 1 hr ago Child (sleeping) <i>mom states child uses pain ruler to inform her of pain.</i>
	26	Parent feels hot to touch (<i>I suggested mom get thermometer from hotel, ice chips</i>), X not in a lot of pain, quiet, afraid to cough, keeps pretty still, not getting medicine into X, X is afraid to open mouth and cough, not keeping any fluids down at all Child throat very very sore, feel sick, taking ice chips, <i>speaking very quietly</i>
	27	
	28	Parent X feels nauseated, I gave Gravol (gave 1 tsp., they recommended 2) 1/2 hr ago, X just woke up, had 2 sips of gingerale, feels warm to touch (no complaints of ear ache) Child awake but doesn't want to talk

	29	Parent X didn't want to drink or eat anything, (drank 1/2 cup so far, 3 tsp. ice cream) Child (sleeping)
	30	Parent X says X is in rough shape, had a piece of freezy, no vomiting at all, not drinking much at all since back home, says it hurts too much, X is hungry ++, can't eat, on no antibiotics Child hurts (throat)

Day	Case	Parent/Child Responses to Questionnaire Item
1	31	Parent X taking fluids, 1/2 cup, vomited not at all, skin warm Child (sleeping)
	32	Parent X in a lot of pain, 2 glasses of fluids all day, try to give X as much as possible, ate pudding, no vomiting (nor in hospital), tummy sore, doesn't feel hot to touch Child (has tummy ache)
	33	Parent X doing very well, no vomiting (I was afraid X would), had 4 oz fluids, a little on the warm side, no pain in ears, just throat Child (sleeping)
	34	Parent X in more pain now, drinking a lot, no fever, no tummy ache, not interested in food but tiring Child sore throat, ears doesn't hurt, drinking very well, not hungry, no tummy ache <i>sounds congested</i>
	35	Parent X drinking about 1/2 glass, feels a bit warm, no vomiting spit out saliva, tying jello Child talking not too good from mouth
	36	Parent X congested, no vomiting, doesn't feel warm, no bleeding, no ear pain Child kind of sore throat, hard to talk, <i>sounds congested</i>
	37	Parent really sick coming home, threw up coming home Child sleeping
	38	Parent X sleeping on and off, vomited in hospital, not now, no stomach ache, feels warm, no bleeding Child sleeping
	39	Parent X vomited x4, started in hospital and just before we left, scaring X, gave oral Gravol, no fever, very little fluids, not drinking much in hospital either, nurses took IV out after vomiting Child sleeping
	40	Parent X all right, uncomfortable, spaced out with medication, threw up x 3 in hospital and 1/2 hr before discharge, no vomiting now, feels nauseated, no bleeding drinking 4 small glasses small popsicles, no fever Child long day

Day	Case	Parent/Child Responses to Questionnaire Item
1	41	Parent family not in Child
	42	Parent X not spitting up blood, drooling, drank in hospital now not had anything, no fever, vomited hospital not at home Child sleeping
	43	Parent X has been up and down, vomit on way home in car, X should have walked out, seems to be fine now, X is worried about coughing, taking popsicles, 8 oz fluids, no vomiting fever nor tummy ache Child sleeping
	44	Parent family not in Child
	45	Parent X drinking a bit more, pain too much, medication help, sleeping, not even drinking 1/2 glass all night, vomited in hospital, they gave us bucket and X threw up in car, a bit of blood, not now, doesn't feel warm, no thermometer Child sleeping
	46	Parent X drank 3 oz, no vomiting, nauseated, no bleeding Child sleeping

Day 1

3. What did doctors, nurses, or other staff tell you about pain after an operation?
4. What did doctors, nurses, or other staff tell you about how to care for (x) after his/her operation?
5. What information did doctors, nurses, or other staff give you about caring for (X)'s pain at home?

Case	Parent Responses to Questionnaire Items
01	3. surgeon told me to administer Tylenol q4h, whatever I had at home, no one told me to expect pain or told me anything about pain, didn't go into it deeply, just Tylenol and liquids 4. regular common sense stuff, quiet, comfortable, rest, no jumping, for 7 days give good care, push fluids, if any signs of bleeding take X to emergency, nurses stressed this. 5. as above, medication, fluids (<i>mom didn't know amount of fluids to give</i>)
02	3. not a heck of a lot about pain, surgeon told me to give Tylenol q4h x 24hr, if still pain then q4h for another 24hr, then prn, nurses gave same instructions verbally 4. Tylenol, ice pack, popsicles, unsure about what to expect regarding X sleepiness and how much fluids should X have ?? (<i>writer advised minimum of 30ml/hr</i>) 5. as above
03	3. give Tylenol q4h, if nausea give Gravol, only about medication 4. keep laying down, give ice chips ice collar, if bleeding phone Dr., if vomiting blood take to emergency dept., nurses gave dad paper, didn't have time to read it 5. good information about monitoring X condition, nurses showed me X's throat and told me what to watch for regarding potential complications, like bleeding
04	3. give Tylenol especially tonight, advised to double the dose, I didn't get much information on fluids, how much fluids I am to give X, told could give X ice pack or cold cloth on face 4. gave a long list of instructions, mostly verbal, soft diet x 3 wk., bedrest x 24 hr., not to go outside for 1 wk, keep head/ears covered, if any blood ears/nose/mouth take X to emergency dept., given white postoperative information sheet, not specific to T&A 5. nothing besides Tylenol, cold fluids
05	3. told to expect quite a bit of pain, don't give dairy products or else X will get stomach upset 4. give clear fluids, Tylenol 2 tsp. q3h x 24hrs (dose as on bottle) keep quiet, let them sleep don't wake up for medication 5. given for verbal/written information, <i>use vaporizer to increase humidity</i>
06	3. told ears could hurt, normal, give Tylenol q4h for 3 days, give as instructed on bottle 4. not too active for couple wks, indoor x 3 days, give lots of fluids, Jell-O, no milk products 5. as above
07	3. Tylenol, give as directed on bottle for first day x 24hrs, nurses said to wait for 4 hrs for next dose but I noticed they gave it q3hr, said can give well over dose on bottle, I'm confused !! Written instructions say can give up to 600 mgs, verbal different. Nurses said (X) would be very uncomfortable for 1 day with time it diminishes, every child is different 4. keep quiet indoors, let sleep, NB to drink both verbal/written information 5. give Tylenol basically, comfort measures, ice collar, ears might bother X
08	3. told there would be a lot of pain, give Tylenol q3-4hr x 24hr then q4h prn, <i>mom thinks combination of too much Tylenol and moving about makin X nauseated, vomiting</i> 4. watch X, make sure to increase fluids, give Pen G and Tylenol, clear fluids today, ice cream tomorrow, soft diet 5. basically Tylenol
09	3. give Tylenol, prescribed Codeine, nurses advised 1/2 dose Tylenol mixed with Codeine 4. nurses went through sheet of paper, said to take it easy for 3 days, stay indoors, that every child recovers differently 5. give Tylenol, watch what you give them to eat

3. What did doctors, nurses, or other staff tell you about pain after an operation?
4. What did doctors, nurses, or other staff tell you about how to care for (x) after his/her operation?
5. What information did doctors, nurses, or other staff give you about caring for (X)'s pain at home?

Case	Parent Responses to Questionnaire Items
10	3. Tylenol q4h x 24hrs, no matter what then prn, stressed very NB for 1st 24hrs, better to control pain, said on Clavulin for bacteria infection 4. how to watch for infection, how to check throat, if has high fever, bleed--> emergency dept., don't go to medi center as not familiar with this OR, gave both verbal written inform, step by step instruction, keep quiet, rest, can't gargle, no straw, don't blow nose, soft diet, 5. only Tylenol, don't give aspirin, cool foods, no milk, stay home avoids people with colds
11	3. nothing about pain after OR, give Tylenol tablets or syrup and follow instructions on bottle, pharmacist suggested I give 1.5 tsp. x 24hs then prn 4. given sheet on T&A, nurse read it aloud, Dr. went over information, they stressed allergies 5. only about Tylenol, nothing about comfort measures
12	3. prepared X for child having pain, child didn't know was going to have surgery until 2 days before, didn't cry, matter of fact, instead of being nervous and worried had good supper night before 4. not to give X anything red colored, clear fluids today, increase to soft tomorrow, keep low activity 3-4 days, if complications (bleed) covered in hand out 5. Tylenol 2 tsp. q3hr x 24hrs, wake X up, don't wait until X asks therefore don't have to play catch up with X pain
13	3. all they said was to take medication q3h 4. if spit up blood to watch for this, didn't say how much, gave sheet re rest, diet, fluids 5. Tylenol #2 q3h x 3 days for sure then prn, then Tylenol extra strength
14	3. nurse common for kids to be nauseated, give Gravol suppository if can't take oral, wake X up in middle of night for Tylenol and drink, set alarm clock 4. nobody told me about how to care for X except 1 nurse, gave us standard T&A sheet 5. Tylenol, if X can't handle Tylenol with Codeine give X Tylenol extra strength
15	3. to make sure Tylenol and fluids given, if hungry feed X 4. I don't know if they did, common sense stuff (fluids, rest) gave both written/verbal 5. Tylenol essentially, Dr. prescribed Codeine (told to use if pain is bad, don't give unless necessary), I don't like over medicating them. Tylenol 2 tabs q3hr, dose written on back of bottle
16	3. told will be very painful, nurses helpful, explained to get X up at night for medication 4. verbal/written, activity, diet, fluids, complications 5. prescription when to give, ice collar
17	3. Dr. nonchalant, said X would be uncomfortable- bounce back quick, nurses descriptive told how much 4. diet, fluids key, complications (written and verbal) 5. keep level of Tylenol up so no hills and valley's, give ice collar, cool mist, ice chips
18	3. keep full of pain killers for last couple of days, q4hr will recover better 4. lots of clear fluids, soft diet, complications on written information, can X have milk today? 5. medication round clock, give popsicles etc.
19	3. last few days will be in a lot of pain, should take medication for next 3 days, fluids, diet 4. mostly written information some before discharge, nurses went over complications, what to look for, explained verbally very well 5. mainly try to keep X wet, give pain killers, impressed with nurses, other mom scared me told me X story, needed to phone home for comfort
20	3. none, said it would be sore and that's it, said for X to drink lots of fluid 4. written sheet, nothing actually, only to give lots of fluids 5. medication Tylenol (dose as on bottle) or codeine (3-5 mls q4-6hr)

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Case	Parent Responses to Questionnaire Items
21	3. gave sheet how many days it would last (3-4 days), what to give and what not to 4. keep quiet x 3 days, take it easy for 1 wk after, keep out of crowds x 1 wk, drink lots, don't cough blow nose 5. codeine 11/4 tsp. qh x 24hrs., told codeine constipating, give Tylenol in-between q3-4h x 24 hr, wake up during night, drink lots
22	3. don't really remember, this time DR more stricter than before esp. re solid foods, no solid food for 2 wks, give medication round clock 4. no straws, medication, went across paper work, what causes bleeding 5. Tylenol 2 tsps q4h x 24 hrs then prn, silicone ear plugs, avoid riding bike, cover ears
23	3. trying to remember, said would be pain and discomfort but not that great, that it would gradually reduce 4. diet, activity, medication Tylenol 240 mg q4h x 24 hrs 5. medication, popsicles, keep fluids up to prevent drying out
24	3. not too much, would have a lot of pain for a few days, 4. verbal/written, Tylenol, what to watch for (bleed), diet, activity 5. Tylenol 2 tsps q3h, wake up at least x 1 tonight with Tylenol, (mom said she is a nurse), being nurse doesn't help knowing it is your child, may know things but still worry the same
25	3. Dr. said to give Tylenol q3h, nurse to give X q3h x 24 hrs, wake up x1 at least during night, to keep throat from drying out 4. nurse, keep in for 7 days, bleed --> emergency dept., gave both written/verbal inform, foods, phone # if needed, care things 5. medication, Tylenol #2, 1 q3h, asked pharmacist for it
26	3. Tylenol basically that's it, it will be sore, one nurse spent time but the other one was quick lets get it done, said in pain for couple of days after should be fine, I need more written inform 4. written inform only, complications not verbal, I asked friend how to look for blood and fever 5. Tylenol that's it, ice collar
27	
28	3. nurse spoke English poor, our nurse didn't tell us anything, gave us paper, Tylenol what dose to give, nothing else 4. paper only, can't remember given verbal, no inform about dehydration, 5. Tylenol 320 mg q3-4 hr as needed, I didn't speak with dr. at all today, got in as cancellation
29	3. not really, I know the calmer you stay pain will go away, Tylenol as on bottle, I heard nurse telling other parent for X weight, inconsistent information, told me give as on bottle 4. give fluids, didn't know how much to give (<i>I suggested minimum of 30 mls/hr.</i>), asked if nurses knew how much popsicles are equiv. to in liquids 5. fact sheet inform about diet, emergency dept. #, child asked if X would die
30	3. X would have pain, more drinks feel better, Tylenol q3-4 hr, will help pain to wake X up so X won't get completely out of pain killers, nurse told me X prob. won't need codeine 4. Dr. didn't say much, X will be fine right away they bounce right back, Tylenol q3-4 h 5. no comfort measures, keep X drinking,

3. What did doctors, nurses, or other staff tell you about pain after an operation?
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Case	Parent Responses to Questionnaire Items
31	3. Tylenol with codeine, unsure of dosage, misunderstood Dr. may have forgotten who they told what to 4. told what to expect, that X would be out of it, can swim in pool, I know what to expect, 5. Tylenol, ice collar
32	3. didn't really say anything other than X would be in pain, gave written inform sheet 4. didn't say a whole lot, diet 5. Tylenol (dose as on bottle) q4-6 hrs,
33	
34	
35	3. gave us pamphlet read out loud, what to look for Tylenol 320 mg q4h x 24hr --> prn 4. read out loud the pamphlet 5. as above
36	3. Tylenol with Codeine elixir 10 mg q4h prn 4. if drooling bring in, lots of rest, lots of fluids. Main concern is 1st 24hr, I'm forced to stay awake all night to ensure (X) OK, (<i>mom afraid she will fall asleep</i>) 5. Tylenol with codeine
37	3. that X would be in a great deal of pain, (<i>mom was concerned codeine would upset child's stomach</i>) 4. gave written information, keep eye on X, no activities for 1 wk, lots of rest and fluids, office nurse told me I would have to watch X all night, I'll stay up all night too worried 5. give Tylenol q4h, ice collar
38	3. X would have pain and needs pain killers, didn't say too much about it 4. gave us photocopied sheet, ph # if we need it, didn't go over it verbally 5. Tylenol #3 1 or 2 tabs q4h, didn't say to wake X up, drink fluids often to keep throat moist, didn't say how much fluids to give
39	3. not a heck of a lot, gave information sheet, give Tylenol q4h dose as on box, didn't say how much pain to expect 4. give medication, lots of fluids (didn't say how much), soft foods, stay away from dairy prod, 5. Tylenol, information sheet mainly, give ice pack
40	3. Dr. said X would be uncomfortable for 2 or 3 days then pain subsides, nurse said uncomfortable for 1 wk, today and tomorrow would be the worst 4. most inform from nurse, clear fluids for 48 hr, if cough up little blood no concern watch X 5. let X have Tylenol as X needs it then if really bad give extra strength at bed time Tylenol 11 q4h x 24 hrs.

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Case	Parent Responses to Questionnaire Items
41	3. Tylenol #2 q4h last couple of days for pain, didn't tell anything, 4. nurses said if X throws up blood, phone them, appointment in 1 wk, soft diet warm soup 5. didn't say to wake up for Tylenol, didn't say give ice pack
42	3. gave inform sheet, DR didn't say anything, no verbal information 4. didn't mention anything about giving red colors, said give lots of fluids both verbally and sheet 5. Codeine, get prescription said it might work better than Tylenol, didn't mention to wake X up at night for medication (<i>writer suggested mom think about this as 7 hr drive home tomorrow</i>)
43	3. X throat would be very sore, in 3 to 4 days should decrease 4. care sheet what to eat/drink/activity, not to gargle, I'm quite informed, hard to remember 5. Tylenol 3 x 2 q4h, leaflet says if sleeping told do not wake up, told this, give ice packs, ice cubes if very sore
44	3. said will have pain up to 6 days give Tylenol q6h unless sleeping at night 4. Tylenol for pain, clear fluids today and next few days (didn't say how much), soft diet, not to cough blow nose or jump around. 5. Tylenol q4h, ice pack
45	3. Tylenol 1.5 tsp. q4h, told us to wake X up for this 4. didn't say much, gave information sheet, I'm tired didn't read, can't read it all, the twins look more tired now, don't have any energy 5. as above
46	3. 4. same as above 5.

Day 2

9). I will begin by asking you how things are going so far for you ... in caring for (X)?

Day	Case	Parent Responses to Questionnaire Items
2	01	bitchy night, X's throat drying out, X woke up at 12 and 4 am, coughing at 2 am, <i>mom slept with X</i>
	02	very well, child did very well, slept at 8 pm, <i>mom slept through night, mom explained to X that if didn't keep fluids up, X would become dehydrated</i>
	03	really good, X is better today
	04	I'm feeling more confident, X is coming around more, slept, dad and other children left for ball tournament, so quiet time less hectic, rested more
	05	testing today, stressful, had other 2 kids to care for, not prepared for X not walking, concerned about ear ache (<i>report from dad, single parent, mom & dad share care taking alternative days</i>)
	06	pretty good, I was worried a lot earlier
	07	all right, X still is having a lot of pain, I slept but up several times with both of them
	08	pretty good, no problem, child didn't sleep well, should I give X 1 instead of 2 pain tablets, X is not throwing up with 1 but did when took 2? <i>dad pharmacists (mom decided on own to give one instead of 2 tablets)</i>
	09	fine, I'm concerned about fluids, have no information about how much fluids to give (<i>I advised mom to give at least 30ml/hr</i>)
	10	so far so good, we had problem last night, didn't hear alarm clock, too tired, gave X Tylenol at 930 am, <i>mom didn't work today</i>

Day	Case	Parent Responses to Questionnaire Items
2	11	not bad, <i>mom reported she didn't get much sleep, child laying in mom's bed, mom asked me when X could go back on milk (I advised mom not today gave 2 reasons for avoidance of milk)</i>
	12	ok, I think I am doing well <i>mom asked me when X could start brushing teeth (I advised mom against gargling)</i>
	13	good, X is doing very well
	14	mom not in
	15	I slept with one eye open, we woke X up at 930 am to drink and eat, X is hard to wake up must have a high threshold
	16	ok, good, husband up at 3 am for medication then me at 7 am
	17	fine, ok, watching X, wishing X didn't feel so mopyy, no questions
	18	good
	19	<i>report from aunt, mom admitted X to hospital, unsure but thinks because child has infection, child had real hard time swallowing, will call back tomorrow</i>
	20	good, I went to work today, my cold a bit better, still there though, slept last night (<i>mom concerned about X not eating, concerned X will lose weight, X prone to this</i>)

Day	Case	Parent Responses to Questionnaire Items
2	21	trying to get X to drink/eat, they should keep in at least overnight cutbacks!
	22	report from baby-sitter, child had throat swelling, ears bleeding, ear infection, parents admitting X into hospital, has blood clot in throat and ears are infected, had very bad pain
	23	good, X didn't want to stay in the house, hard to keep X in, playing with friends now, no questions
	24	really good today, pleased X is doing so well, no questions
	25	family not in
	26	feels good to be back at home, yesterday X stopped throwing up, X didn't want suppository, I told X, X would have to get the medication -- X stopped!, started drinking more and more" <i>mom asking about pain in neck and shoulder area</i>
	27	unable to contact family
	28	pretty good, this AM was tough, had to explain what would happen if X didn't drink, its tough-tough-tough knowing what to feed X, X slept with dad for comfort, hard to tell if dehydrated, if X were in hospital they would understand what X needs, I'm still upset with the lack of information, there was a cancellation so they took us, hospital called us collect, it is done and over with anyway, maybe different experience going out of town
	29	good ,better than what expected, too good to be true, only child so gets lots of rest, no interruptions (<i>mom not working, single parent, grandma staying overnight</i>)
	30	not too bad, X getting better, doing a lot better, not energized, says Tylenol doesn't help

Day	Case	Parent Responses to Questionnaire Items
2	31	good, X amazingly better, no questions
	32	pretty good, no questions
	33	not badly, I'm tired, painting house, feeling insecure at times, X is quiet, congested having a hard time breathing" asked how could reduce nasal congestion (<i>recommended increasing humidity, phoning Dr. for decongestant</i>)
	34	fine, no problem at all, however X's chest not better, day surgery nurse called they suggested X breathe deeply, mom wants to cut back on Tylenol #3, asked what should she do <i>I suggested pain could be due to anesthetic, pleuritic or gas pain - recommended she contact Dr. if concerned</i>
	35	better now than 1st day, X is better now
	36	fine
	37	mom not in until 10 pm (went to Bingo), older sister taking care
	38	little sleep, very hard to stay in hotel, not very comfortable, any idea how many more days X will be like this?
	39	little concerned not drinking as much as X should
	40	family not in

Day	Case	Parent Responses to Questionnaire Items
2	41	mom not in
	42	unable to reach family, rural
	43	unable to reach family, rural
	44	good, X has been in bed all day
	45	I'm tired, didn't sleep much, worried, X won't listen to me, X won't drink
	46	as above, like sibling, why they won't drink, why so much down?

Day 2

10). How are things going for (X) ?

Day	Case	Parent/Child Responses to Questionnaire Item
2	01	Parent X doing all right, outside now playing with friends, not much appetite today, a bit nauseated this am, had poached egg, have to encourage fluids, food, had sore throat this am Child good, throat sore in AM
	02	Parent X slept through night, didn't take medicine at night, woke up with excruciating sore throat Child feeling a bit better, throat still a bit sore
	03	Parent X better, still sore swallowing, appetite still poor, slept through night, taking lots of ice chips, water Child a little sore, still can't swallow that good, slept through night, voice better now
	04	Parent X little bit better this afternoon, not taking Tylenol after 8 pm, threw up, awoke once during night, slept until 9 am, today rough am until noon, had broth and Tylenol, ate egg, slept, taking fluids ++ Child feeling better, slept, drinking
	05	Parent X has high fever 101.8, couldn't walk, ear ache, didn't want to drink, I called family Dr., gave us Tylenol with Codeine, has pain says it hurts so much this afternoon, happier now, Dr. states X will get grumpy with plain Tylenol, walking now, drinking now Child (child sleeping)
	06	Parent X went to bed 11 pm, up 930 am, slept very good, had sore throat a lot this am, drinking apple juice, complained a lot of pain this am, no vomiting, had fever this am no fever now, looks weak, no major problems now Child a bit sore, medication helps, drinking
	07	Parent medication not lasting, giving it q3h, X constantly complaining, got up once otherwise slept through night, when awake really sore, drinking quite a bit, appetite hungry but no eating, no vomiting, just resting watching TV" mom asking me if she should give X Tylenol q2h? amount of Tylenol prescribed is not enough <i>I advised mom to contact surgeon, family Dr. or hospital</i> Child I'm ok, throat hurts
	08	Parent X up vomiting 2 or 3 times during night, quite miserable, dizzy, sore throat, nauseated, drinking milk shake, popsicles, no vomiting yet today, <i>mom unsure about how much analgesic to give as child vomiting but in pain. I advised mom to contact family Dr. regarding Gravol, discussed cycle of pain</i> Child (didn't want to talk, hurts too much, dizzy when up)
	09	Parent X has been pretty slow, not talking at all, not drinking much had 8 oz all day, active this afternoon, slept but up X 3, not eating much, throat pain primary problem
	10	Parent X not eating very much, X is trying so I am not forcing, had potatoes gravy, drinking lots of apple juice, couple glasses of water, no tummy ache, diarrhea a bit, no ear ache, awake crying on and off Child throat not very good, am I allowed to eat french fries ? (<i>no, not yet</i>), can I eat macaroni ? (<i>ok</i>)

Day	Case	Parent/Child Responses to Questionnaire Item
2	11	Parent (dad) X ate soup, alpha getti, fluids not too bad (5 cups apple juice, tea, jello), no vomiting, a bit of upset stomach, no complaints of pain, staying calm, no fever
	12	Parent X has sore jaw, vomiting started today, by lunch X's stomach was empty, had soft bread, seemed to help, blood came with that too, no fresh bleeding, none, no drainage from ears, pushing fluids, milk even this afternoon Child throat sore, ears good
	13	Parent family not in Child
	14	Parent mom not in Child not too bad, slept through night unless for pills, sore when awake, still is, drinking 2-3 glasses per hr, eating popsicles, pudding, ice cream, porridge
	15	Parent X doing quite well, playing it by ear, no vomiting since last night, eating eggs, popsicles, soup and cake, drinking 1 glass fluids/hr, slept last night had to wake up to give medication, will play it by ear tonight for medication, if X doesn't want it, I won't force, on tummy ache, no fever Child good, drinking lots, throat hurts to swallow
	16	Parent X still in a lot of pain, reluctant to drink, gave flat gingerale, had 2 popsicles, 1/2 glass water, Codeine 4 times, vomiting a bit 2 or 3 times last night, no vomiting now, no fever, ear ache on one side I suggested humidifier Child (child sleeping)
	17	Parent X is moppy, a bit better, went outside a bit, softer diet, no vomiting, had upset stomach today gave X Tylenol, no bleeding Child ear feels better (slept through night, this AM throat really sore and dry, had 1 1/2 glasses water, not really hungry,
	18	Parent X still sore, eating a bit more, salad, lots of fluids, no vomiting, no stomach ache, no fever, slept until 10 am Child (child sleeping)
	19	Parent X had hard time swallowing on the bus ride home, took X to see Dr. He found X had pus near the operation and wanted to admit X to get rid of the infection, he put X on IV antibiotics, in hospital now
	20	Parent X slept through night, woke up at 3 am with sore throat, ate macaroni and cheese today, worried about X not eating, drinking lots, no tummy ache, no ear ache, X is self today Child doesn't hurt, drinking apple juice and water

Day	Case	Parent/Child Responses to Questionnaire Item
2	21	Parent X slept through night, no vomiting, spit up some red stuff small amount but not today, no fever but warm to touch, mom stated X is too afraid to talk because of pain, asked writer to speak with child. (told child I understood, spoke about cycle of pain and setting daily goals for fluid intake) Child would not talk at all
	22	report from baby-sitter, X had very bad pain, ears and throat are infected, admitting X to hospital now, has blood clot in throat. Child in hospital
	23	Parent good actually, X feeling not bad, no complaints, drinking OK, eats lots of popsicles, tried porridge & egg, no vomiting, no upset stomach, no fever- felt a bit warm when upset (wanted to go outside) Child good, no ear ache, throat kind of hurts when swallow, lots of pop, outside playing

24	Parent X slept through night, woke X for Tylenol, glass of juice, taking at least 1/4 cup/hr fluids, no tummy ache, appetite ++, doing very well, ear ache today, bit of fever Child hurts when swallow, hungry for toast
25	Parent X a lot better today, drinking soup eating jello ice cream, slept well, woke once for Tylenol and water, not as afraid as yesterday, no tummy ache, no ear ache Child fine, throat sore in early AM, drinking more
26	Parent at lunch time X had ice cream, tired a hot dog, complains hard to swallow, drinking, slept last night very well, had trouble getting back to sleep though, had headache, complained ears hurt Child good to be back home, tummy better
27	Parent Child
28	Parent X drinking 1/4 cup each time, ice cream got mucousy, spat up clear sticky stuff, no vomiting, no upset stomach, slept last night but up 3 or 4 times for Tylenol and drink, feels hot to touch, no thermometer Child "kind of good, throat hurts (<i>sounds hoarse, breathless</i>)
29	Parent X moaned and groaned most of night, hard time falling asleep, 8 oz fluids so far today, eating jello, ice cream and had fruit snacks, slight fever, laying down, moody and irritable, no vomiting, no bleeding, ears not sore Child (child sleeping)
30	Parent X slept until 2 am, hurting, up until 430 am, had long nap, taking enough fluids, had cold soup, no fever, vomited this am, little colored red (had red freezy) Child neck sore

Day	Case	Parent/Child Responses to Questionnaire Item
2	31	Parent X slept all night, woke up with sore throat, having lots of fluids, popsicles, hungry, no fever, no vomiting Child drinking well, ears hurt
	32	Parent X woke up at 430 am, slept, put on humidifier today better, no nausea, little fever, no bleeding, had 1 1/2 cup herbal tea Child good
	33	Parent X congested, having a hard time breathing, total mouth breathing, taking 3 glasses water/day, no food other than apple sauce for crushed medicine, no signs of fever, ears not sore, pain is manageable, watched TV, sleeping now Child sleeping
	34	Parent no fever at all, X drinking well Child still sore throat and chest, slept ok, awake few times had to go to wash room, sharp pain when breathing in, congested, not very good eating, taking lots of fluids
	35	Parent X eating macaroni, drinking gingerale, talking more today, yesterday wouldn't talk wrote down what wanted, up watching TV, playing games, no fever, no upset tummy, slept well, up at 3 am whimpering in sleep Child good, drinking well about 1 glass, doesn't hurt as much with gingerale, sleeping pretty good, didn't throw up
	36	Parent X running a bit of a fever, tired didn't want anything, chills, has a tummy ache, no bleeding, no sore ears, throat sore, no vomiting Child not very good, throat hurts all the time, drinking lots
	37	Parent X feeling a bit better

		Child good, better today didn't sleep mom woke up for medication, vomited x2 this am, no tummy ache now
	38	Parent X really bad night increased Tylenol, hurts to talk, pretty sore, drinking fair amount, little fever this am ok now, no vomiting Child no tummy ache
	39	Parent X not drinking as much as should, trying to, coaxing taking only a few sips, no Tylenol got sick x4 at night, had fever 99, no tummy ache, (writer explained to mom requirements for Tylenol and fluids) Child its sore
	40	Parent family not in Child

Day	Case	Parent/Child Responses to Questionnaire Item
2	41	parent not that good, X not throwing up but both ears hurt, nose plugged, doesn't feel hot, no bleeding, medication helps a bit, drinking 11/2 glasses/day (advised to increase fluids 30ml/hr) child ok
	42	parent unable to reach family child sleeping
	43	parent X seems perkier, doing not too badly, less pain, talking more, relaxing reading, drinking 3 glasses/day, taking hardly any food, no bleeding, no fever, swollen back of throat, age makes difference harder time, slept quite good, up at 3 am analgesics, ears started to hurt a bit, started with this last night, no nasal congestion child sleeping
	44	parent no vomiting, X spit out clear, not swallowing at all, taking hardly any fluids, last night started taking sips, mom gave Tylenol suppository, child sleeping
	45	parent X feels dizzy, nausea, vomited couple of times, not drinking anything (2 spoonfuls total), sleeping a lot, tired dizzy, no fever 37.5, has pain in ears, no bleeding (writer suggested mom encourage fluids 30 ml/hr, give Gravol) child drinking, ears hurt why? (spoke about ear pain, writer also went over amount to drink, encouraged child, discussed pain cycle)
	46	parent not drinking much, few drops in mouth about 1/2 cup all day, wants to cough, sleeping a lot, no fever, pain in throat, no bleeding child went over same information as with sibling above

Day 3

12). How are things going so far for you ... in caring for (X)?

Day	Case	Parent Responses to Questionnaire Item
3	01	not a bad night, I took day off work today to be with X, nice time together
	02	today more hectic, had some problems today regarding X staying indoors and encouraging X to eat, X also doesn't want to take antibiotic but I guess that is kid stuff, told X had to have it
	03	good today, feel X getting better as well
	04	good, X getting back to normal
	05	smoother than yesterday, X feeling better more relaxed, good to see X is getting back to old self
	06	it is ok, but X is not eating and doesn't want to talk, I don't know what to do, I am not giving Tylenol because X has no fever, I am afraid to give it - they get sick if too much medicine (diarrhea, upset stomach), scared they will get this if I give Tylenol (<i>I explained Tylenol ok for fever also ok for pain, explained cycle of pain, mom stated she will think about giving X Tylenol for tonight</i>)
	07	stressful, X said couldn't breath, I don't know why X said that, X had a bit of a fit this am, rolling around the floor, refusing medication, I phoned the number of the sheet the hospital gave me, they said to give X extra strength Tylenol, I crushed this up with jam and gave it
	08	fine, wonder about ears, is it common for them to have ear aches?, using ice collar, X finds it helpful
	09	dad: good, .. wife doing all work, she has the night off went out for dinner with her friends"
	10	good, I'm really tired, my cold is hanging on, sinus infection, headaches, very tired, child awoke off and on until 3 am, settled now

Day	Case	Parent Responses to Questionnaire Item
3	11	not too bad
	12	just fine today, no problems, no questions
	13	things going pretty good, no questions, X is doing fine
	14	hardest time is when I have to leave X alone, I have to work, medication is enough but q3h not q4h, if sleeps past 3 or 4 hours in between taking medication X then really wants them, doesn't bother me, if X needs them X needs them
	15	really really good
	16	dad: X doing fine, handling it well, made X baby food mom: good, feeling better today can see it
	17	easy, been easy day, child taking care of self now, hard in beginning, pretty quiet, my care is easy
	18	mom at work
	19	stressful now with X being in hospital, have to work, have 2 teenage boys at home, then visit X- hard for me
	20	better, X getting there, worked today, don't know how X would be at daycare, did well though

Day	Case	Parent Responses to Questionnaire Item
3	21	getting better, took to Dr. as X had rash from antibiotic, Dr. took swab from throat as it looked red, see tomorrow, X didn't want to take pain medication
	22	just came home at 6 pm today, traumatic up and down, child still in hospital, nurses gave Tylenol round the clock and cortisone, had not had fluids for past

		24hrs (asked mom if she wished for me to continue calling her, mom said she would appreciate same)
	23	fine
	24	pretty good, how long should I continue to wake X up, how long worry about hemorrhage? My other child was a lot sicker, X is doing great, I have to encourage X to keep quiet, running wants to get going
	25	mom and dad not in
	26	pretty good
	27	
	28	fine, excellent, eating, not worrying, relief is over, why would X have pain behind ears after eating? Why was X wheezy after taking milk?
	29	lousy, I have cabin fever
	30	today I went to work, dad looked after X, X had soup, when to increase diet?

Day	Case	Parent Responses to Questionnaire Item
3	31	very well
	32	pretty good
	33	we had had quite the day, X is very stubborn, anxious time to get X to come around, tried to give X control of medication, X refused to take any, can't face pain at all, I explained what would happen if refused all medication (analgesic and antibiotics) fluids and food, X thought about it then in a few hours asked if X could take liquid Tylenol, had some fluids, I am concerned X may not have enough liquids - pain cycle then, X had a good think about it, I am optimistic
	34	pretty good, concerned throwing up and nauseated, chest pain gone, X doesn't want to take Tylenol, if X can do without it then I'll cut back, this might be making X ill
	35	busy
	36	not in
	37	good
	38	not in
	39	pretty good today
	40	today pretty good, is it normal for throat to look white?

Day	Case	Parent Responses to Questionnaire Item
2	41	dad: no problem, X is very good, not a baby, doesn't want Codeine, constipated, will go with extra strength Tylenol (nurse suggested this before discharge)
	42	unable to reach family
	43	mom working all day, sister said X did very well, no problem, wants to cough, very thick phlegm, is this normal?
	44	unable to contact family
	45	I'm scared, they won't listen to me
	46	as above

Day 3

13). How are things going for (X) ... so far?

Day	Case	Parent/Child Responses to Questionnaire Item
3	01	Parent: X is feeling rotten this am with sore tummy, tired today overdid self yesterday, sore, hungry, has appetite now, tummy problems because of having all that Tylenol and not much food, slept through the night, tummy better after giving Gravol, throat still a bit sore (child also on antibiotic) Child: child sleeping
	02	Parent: X is getting impatient, miserable because X wants to eat and play, up middle of night, crying of sore throat, went back to sleep, drinking more than normal, not well eating sore ear this afternoon" Child: throat sore, can't open mouth very wide
	03	Parent: X slept good, jello, ice chips only yesterday, beginning to eat a bit more, still reluctant to swallow much Child: getting better, throat feels like a ball in there, slept well, has white patches on throat, it normal?
	04	Parent: rough morning, X has sore throat and ears, trying to blow nose, after Tylenol perky, no vomiting, slept through night Child: "throat hurts a little, hurts more in am, feels ok now"
	05	Parent: took X out to park, X feeling better, feeling tired, no nausea, drinking a bit every hour, picking up a bit more activity wise Child: throat still sore, ears sore, went to store, playground
	06	Parent: X has not had Tylenol today, no fever, sore all day today, not talking at all today, everything fine, don't know what to do, X is drinking but I force him, force food, X won't eat on own, is not self Child: good, bad throat, ears ok, hurt to swallow, no upset tummy
	07	Parent: X slept through night, this am very bad, screaming at 10 am, day surgery nurses suggested extra strength Tylenol, grandma (nurse) suggested decongestant and heating pad, Tylenol not strong enough, wants another dose only an hour after the last one, don't know what to do for X (<i>writer suggested mom contact Dr. to get alternative analgesic, discussed cycle of pain</i>) Child: good, sort of sore when swallow, slept through night, no vomiting, no nausea, had couple of glasses liquid
	08	Parent: X getting better, still in bed, slept well last night, fluids not much today, ears hurting today, not nauseated Child: <i>doesn't want to come to phone, told mom it hurts to talk</i>
	09	Parent: throat still sore, no ear aches, X still not hungry, doesn't want anything, awake most of day, unsure if slept through night, drinking about 1 liter/day, no tummy ache
	10	Parent: X seems to be all right, throat very sore in am, pain at top in am, not having much fluids, have to force, appetite better, a bit of tummy ache from medication, up on and off, crying whimpering in sleep, drank from straw mom forgot Child: kind of good, bad bad throat, ears real great (<i>spoke with child regarding NB of fluids, mom requested I do so, set daily goal for fluid and food intake</i>)

Day	Case	Parent/Child Responses to Questionnaire Item
3	11	Parent: X was sore this am, not a great appetite, not drinking liquids as well, slept well, active ++
	12	Parent: X out riding bike, had 6 glasses fluids plus popsicles etc, had hot dog, no spicy foods, tired now, no fever, slept until 5 am, up to have water, coughing, no Tylenol today, will give at bedtime Child: throat pretty good, ears pretty good, swallowing hurts
	13	Parent: Child:
	14	Parent: X had rough day today, worse than yesterday, hurting more than X expected, this surgery the worst of any X has had, frustrated has to stay at home, can't hardly talk, not working today, stupid sore throat" Child: unable to talk
	15	Parent: fine, X slept through night without medication, slept until 930 am, pancakes for breakfast, fluid intake good, no vomiting, no tummy ache, no fever, swimming now Child: swimming
	16	Parent: dad X doing pretty good, encouraging fluids, better, drinking more, really hungry, sleep through night, no vomiting no upset stomach Child: ok, sore, especially in am, sore throat and ears
	17	Parent: X doing fine, ok, went out to library, talking more, voice still a bit hoarse, slept through night Child: pretty well, books reading, ears not sore
	18	Parent: mom at work Child: not bad, sore still when swallow, right ear hurts a lot, feels like I am out of balance, no drainage, upset stomach this am, up one a while at night, taking popsicles, pudding, noodles, jaw and tongue sore
	19	Parent: X had a lot of pain, doing better now, was dehydrated, trouble falling asleep in hospital Child: in hospital
	20	Parent: X slept through night, woke up at 3 am, crying sore throat, ate macaroni, worried about X not eating, drinking lots, no stomach ache, no ear ache, Child: not hurting, drinking apple juice and water

Day	Case	Parent/Child Responses to Questionnaire Item
3	21	Parent: X eating a bit more, Chinese food, drinking well, Dr. took X off antibiotic as had rash, gave X ointment for head, feeling better, slept well, no tummy ache, feels a bit warm Child: good, not much appetite, drinking 1/3 cup water/hr
	22	Parent: X drinking much better today, in a lot of pain from ears, sensitive ++ in hospital told me to keep ears covered Child: sleeping
	23	Parent: X didn't have a good night, had nightmares, up screaming, laying around most of the day, no eating as much, drinking about 1/4 cup, upset stomach (clavulin), no fever Child: throat sore today, ears don't hurt, hard to drink
	24	Parent: really good, X slept through night, didn't wake X for medication, drinking well, soft foods, no stomach upset, had toast with crust cut off, tired, throat bad in am, good appetite, no fever, ears hurt today and a bit yesterday Child: good, not that bad throat, hungry, ears hurt

	25	Parent: mom and dad not in Child: feeling better, hurt in am, ears don't hurt
	26	Parent: X has a bit of fever today drinking little at a time, no vomiting, spit is very thick, trouble swallowing Child: throat sore, can't hear properly from ears (<i>I spoke with child on mom's request, suggested to child that she set daily goals for fluid and food intake, discussed cycle of pain</i>)
	27	Parent: family not in Child:
	28	Parent: X slept through night, drinking really good, not dehydrated, eating better, no vomiting, no fever Child: feeling a bit better, eating, drinking, <i>sound breathless, mom says normal voice since node biopsy</i>
	29	Parent: X woke up 230 am crying, not feeling good, this am same way, took X out for a drive, sore stomach, drinking 12 oz/today, no fever Child: good, drinking a lot
	30	Parent: X eating yop + +. Soup, noodles, picker eater, no fever Child: throat hurts, ears no pain, slept, had soup

Day	Case	Parent/Child Responses to Questionnaire Item
3	31	Parent: very well, hardly any pain, X eating, starving, drinking a lot, no fever, no ear pain, no tummy ache, awoke complaining of pain last night Child: "very good, drinking well, swimming"
	32	Parent: X tired and cranky, sleeping pretty good, no stomach ache, drinking pretty good, popsicles, feels a bit warm, had cheese, cream of wheat, rice Child: sleeping
	33	Parent: X awoke 1030, didn't take Tylenol, antibiotics nor fluids because it hurts, I had to pull the mom routine, told X reality of situation if didn't drink, take medicines, X asked if could take liquid Tylenol, I said yes, X was 6 1/2 hr. without medication, sleeping since, no fever Child: sleeping
	34	Parent: X threw up yesterday, feels hot, strip says fever, had fever after Tylenol only once today, gave X cool cloth, went away, chest pain all gone Child: not very good, pain in throat bad, chest pain better, drinking pretty good, not eating
	35	Parent: nanny busy Child: good, a little bit bad, throat hurts, good sleep, 5 glasses water, no bleeding, ate frozen yogurt, no upset tummy, hungry
	36	Parent: X had fever last night Child:
	37	Parent: X gone to movie, pain hits X at night, cry's with it, fever, eating quite a bit soft foods, refuses to take any medication, gave Gravol suppository, drinking a lot Child: not in
	38	Parent: parents not in Child: good, better, drinking lots, taking Tylenol, slept through night, no tummy ache, don't feel warm (<i>sounds nasally congested</i>)
	39	Parent: X drinking pretty good, 2 Tylenol only, chipper, talking + +, braving it right through, no Gravol, no tummy ache, no fever, drinking 5 glasses, better appetite, sleeping well, X is responsible Child: good, I am taking Tylenol.

	40	Parent: X sleeping a lot, a little bit of pain, Tylenol doesn't seem to work, X feels it all the time, drinking 5-6 glasses/day, eating soup, no fever no vomiting, slept well, in tears until next pill Child: ok still hurts
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Day	Case	Parent/Child Responses to Questionnaire Item
3/	41	Parent: X drinking 2 1/2 glasses/day, bit of jello, no fever, not vomiting nausea, doesn't like taste of medicine, ears hurt, a lot more pain today Child: ok, hurts a bit, sort of slept well, drinking lots (<i>sounds congested</i>)
	42	Parent: ok with medicine, when wears off X in lots of pain, mixing Tylenol with Codeine, taking 3 glasses fluid/day, on fever, no bleeding, slept last night Child: sleeping
	43	Parent: X didn't wake up last night, had good sleep, taking 3-4 glasses fluid/day, ate mashed potatoes, no fever Child: have thick phlegm, both ears hurt
	44	Parent: unable to contact family Child:
	45	Parent: X vomiting every time X has anything, dizzy all the time, walks only to toilet, sleepy, X won't take pills, will try to get liquid Gravol, temp 37.5 on fever, lots of pain in stomach. (<i>After speaking with sister, apparent that child has rash that comes and goes,, abdominal pain after taking codeine syrup, writer advised mom to stop codeine switch to Tylenol liquid as child might have allergy to Codeine, encourage fluids 30ml/hr, contact day surgery # on sheet or contact Dr. (surgeon or family) about same</i>) Child: sleeping
	46	Parent: X is doing better than sibling above, I worry more for X above, this X had 1 cup soup, not sleeping well, will drink only if I push, they won't listen to me, I tell them they will have problems go back to hospital if don't drink, they won't listen, afraid (afraid to drink and vomit and have pain) (<i>discussed cycle of pain with X, suggested X set daily fluid and food goal, mom requested I speak with other child (# 45) as well</i>) Child: sore throat, hurts to swallow

Day 4

15). How are things going so far for you ... in caring for (X)?

Day	Case	Parent Responses to Questionnaire Item
4	01	went really well, fantastic am, I was working this am, gave X extra care, home with X in afternoon
	02	much better for me today, X slept through night but was fussy at midnight, crying, I am less worried, fear down of complications (bleeding and infection)
	03	mom and dad out
	04	very good, can't believe how one day X is laying out on the couch and the next up and back to old self
	05	pretty good, watching X, sibling broke out with chicken pox
	06	mom and dad not it, teenage sister in
	07	pretty good, no problems today, starting to subside, so much different than yesterday
	08	dad: I am ok, looking after X today all day, I don't think there is a problem, X seems to be ok but still has sore throat. Do they use stitches?, should X be this lethargic?
	09	fine, a little tired, I worked today, dad stayed with X in am, me afternoon"
	10	good, fine, how long before X can blow nose?

Day	Case	Parent Responses to Questionnaire Item
4	11	really good, concerned - realize slow recovery, X is slow to appetite
	12	ok, I am pleased with how X is doing, <i>mom asking how other kids doing</i>
	13	parent not in
	14	not too bad, X is doing ok, it will be a matter of time before X gets better
	15	dad: fine, no problems at all, mom out
	16	good
	17	my day very easy
	18	dad: X doing ok. mom: good really good, everything back to normal
	19	stressful, hard not having a phone, living in trailer, I am taking tomorrow off, X may come home tomorrow or today
	20	good, my back is sore today, working today, Is throat suppose to be white?

Day	Case	Parent Responses to Questionnaire Item
4	21	mom not in
	22	child back home
	23	good
	24	good, thrilled doing so well, too good to believe, I am not worried
	25	dad: good, X recovers very fast, gets over it very fast, mom working, how long is X bad for colds?
	26	working today, good, I'm not here to give medicine, X is not taking it as X should be
	27	unable to contact family
	28	excellent!, everything back to normal, no pain medicine required
	29	not getting up, still snoring why?, when can give toast, food?
	30	pretty good today, not working today

Day	Case	Parent Responses to Questionnaire Item
4	31	good
	32	we saw Dr. today, says X doing good
	33	pretty good, better day, some moments I feel a little out of control, don't know how some are doing this, I have no work this summer, lots of support, last night checked my perceptions with friend who is a nurse, I am fairly educated
	34	mom not in
	35	ok
	36	ok, I'm working now, good in dayhome have excellent baby-sitter
	37	mom not in
	38	a lot better
	39	not too bad, he has been pretty good
	40	pretty good today, feeling a lot better, not sleeping much

Day	Case	Parent Responses to Questionnaire Item
4	41	pretty good, not much problem
	42	unable to reach family
	43	pretty good, worked this am, sister looking after X
	44	slept well
	45	scared, worried something will happen, X doesn't take medicine anymore, crying at night, don't have prescription for Tylenol didn't get (writer explained no prescription required for liquid Tylenol, encouraged mom to obtain, contact Dr. or pediatric unit if concerned)
	46	I'm not all right, tired, with both of them hard, X crying scared why throat white, scared something wrong, please tell X she will be ok, scared, won't listen to me.

Day 4

16). How are things going for (X) .. so far?

Day	Case	Parent/Child Responses to Questionnaire Item
4	01	parent: X attitude fine, tremendous night, X slept through, eating, not huge appetite child: good, little better, eating too much popsicles
	02	parent: much better, X ate piece of cake last, night-felt better, ate hot dog(small pieces), fluids still pushed-reluctant to drink on own child: feel better, throat still hurts
	03	parent: good activity-better than yesterday, X can hardly feel it, spit out little black thing-little bit, no blood, slept through night-no vomiting, drinking ok-drunk one cup of gingerale
	04	parent: X much better-back to normal, good eating-soufflé-rice, fluids ok, slept through night child: feel ok today, throat still hurt, swallowing still hurts a bit
	05	parent: X feeling better but has the chicken pox, broken out in rash, a few spots, looks good, eating bread and hot dogs, says throat hurts, sleeps well through night, has ear ache child: good, fine, ear hurt-both
	06	parent: a lot better today, X talking, yesterday refused to talk, eating better but still not much, drinking more, encourage child: good sleep, good, feeling better, throat better this morning, still sore to swallow, had tummy ache
	07	parent: X slept well last night, woke up at 6:30 am, still no appetite, not hungry, still drinking a little, no tummy ache, ears bothering a bit, getting better, not like yesterday at all, went out to a movie today child: good, saw movies, ears still hurt a bit, hurts still when swallowing
	08	parent: still very sore throat, X reluctant to eat- has to be encouraged, decrease in energy, laying around a lot, doesn't want to talk too much, ensure places glass water by bed, milkshake, coke and glass, a bit dizzy, doesn't want to get up, had one tablet today child: ear ache, swallowing a lot makes feel better
	09	parent: X better, much better today, getting back to normal self, starting to eat-soup- freezy, doesn't take pain killer until tonight, fluid intake good-playing game, no tummy aches, one eye blood shut, woke up one time
	10	parent: X drinks well, sleeping well, diet good, eats more- french fries, upset tummy not as much

Day	Case	Parent/ Child Responses to Questionnaire Items
4	11	parent: X is good patient, soft foods-pepper-Mexican food, complains of pain-just when swallowing, fluids a lot- 1/4 cup at time, 9 hr, sleeping through night, upset tummy-stomach irritability
	12	parent: other side of jaw hurt today, X said hearing better now, maybe X lived with it for so long now, things are better
	13	parent X complaining a lot this am of sore throat, not eating appetite good though, slept through night, not asking for medication as often, given twice daily, tomorrow wants to go to beach, don't know if X should go child have a bit of ear ache today
	14	parent handed phone to child child have upset stomach, throat better, drinking lots, slept through night

	15	parent dad: X good today, slept through night, drinking fine, diet good,, no tummy ache, no fever child: good, throat sore in am, not really now, ears not sore, hungry eating good, slept through night, drinking couple cups fluids
	16	parent: good, X feeling better child: better, throat better, throat swelling- doesn't hurt as much, little ear ache, slept- but had trouble getting to sleep, no tummy ache, no bleeding, fluids every 2 hr., food- hungry
	17	parent: X had one short cry, yelling at dog, diet- trying but taking fluids only, instant milk, rice milk seemed all right child: not very good morning, at 10:30 had Tylenol, drinking a bit more, no questions
	18	parent: X getting better, eating food, pain down, fluids- drinking lots, no upset tummy, slept all night, voice sounds better today
	19	parent: X had lots of pain, told me it would be the very top of pain scale for the first couple of days back home, I will get X to mark the ruler, still not wanting to eat or drink, really have to push X, unable to sleep until 12 midnight, strange noises, hard to get to rest in hospital
	20	parent: good, ate wiener, potato, posicles, drinking lots, no ear aches, slept rough night, woke up whining/crying, didn't know what was wrong and woke up, took to family Dr. to touch basis child: good, feel ok, dreamed about jail, scared me, eating macaroni and cheese

Day	Case	Parent/ Child Responses to Questionnaire Items
4	21	parent X doing pretty good, eating drinking quite a bit, going out
	22	parent up and about, drinking a bit more, not much, no fever today, slept, eating a bit more, ears sore ++ throat, voice sounds scratchy child: good, hungry eating, trying to drink
	23	parent X ate better, soup, cheese, sandwich, actually drinking better (2 1/2 glasses, slept through night, no fever, no upset stomach yesterday child good, throat and ears no pain, eating hungry, eating drinking
	24	parent X bouncing around, really well, slept through, taking Tylenol, has no pain, drinking and eating well, yogurt jello soft toast ice cream & popsicles child no sore throat or sore ear, eating and drinking good
	25	parent mom not in child fine, throat good, ears no pain, getting better, eating good, drinking lots
	26	parent X is feeling better, drinking better, good, slept through night child good, drinking more, quite a bit (3 glasses), throat sort of pain, ears no pain, no upset tummy
	27	unable to reach family
	28	parent X playing, great except X not eating well, fluids fine, no vomiting or fever, slept well, up at 9 am child good, throat feels better, drinking well
	29	parent X slept all night, this am a bit sore, not eating until Tylenol, improving with fluids although not a whole lot, drinking gradually more, not having to remind constantly, had more solid food, no tummy ache fever or ear ache child feeling a bit better, doing fine with mom, watching movies, drinking lots
	30	parent X up until midnight, drinking less than X should, eating lots of freezy, no appetite, no fever stomach ache child good, hardly any pain, not eating very much, am hungry

Day	Case	Parent/ Child Responses to Questionnaire Items
4	31	parent think X doing very good, slept all night, drinking well, trying to eat, no vomiting stomach ache bleeding nor ear ache child pretty good, went swimming, no ear pain
	32	parent X has more pain in am, taking lots of fluids, eating more, no fever, has runs tummy ache child really good
	33	parent X had quite a few popsicles & water, had fever low grade, better taking medication today, upset tummy last night, heaving, has lots of mucous, afraid to swallow because of pain, up a few times, had trouble sleeping, slept in my bed child ok, coming along, I expect this much pain, lots of people have told me- helped prepare me, drinking (<i>nose sounds congested</i>)
	34	parent fluids ok, 8 glasses water, X eating better, no fever, medication gives headache, don't know if it really helps, no nasal congestion child better, throat better, still hurts, ears don't hurt, no vomiting
	35	parent X doing great now, speedy recovery now, ate french fries yesterday, drinking great, no vomiting fever child feeling better, throat sore, slept all night, drinking 3 glasses/day
	36	parent X drinking good, eating good, more than yesterday, feeling better, no fever, sleeping good, snoring louder, no tummy ache bleeding going ok eating hamburger and french fries child good, drinking eating good, no ear pain, mouth sore
	37	parent mom not in child good throat, no pain in ears, slept good, no vomiting sore tummy, don't feel hot, drinking 4 glasses/day, eating eat sandwiches
	38	parent X eating more, really good spirits, interested in things, doesn't lay around as much, good night, still nasally congested, a bit better, 3 glasses juice, appetite, no fever vomiting, slept well 1st time last night, no ear ache, hearing better now child fine, eating, no nasal congestion
	39	parent X ate hot dog and milk shake, a bit sore throat, trying hard, 5-6 glasses water day, no vomiting bleeding temp, slept through night, tired not napping child good, up 5:30 am play video game, ears a little sore
	40	parent X drinking 4-5 glasses/day, eating soft diet, slept through night, no upset tummy, no bleeding, pain in am a lot child ate french fries

Day	Case	Parent/ Child Responses to Questionnaire Items
4	41	parent ok, X doing fine, a bit of ear ache, actually crying from ear pain earlier today, no fever at all child good, better, up a bit last night, drinking a lot, eating a bit, a bit of ear ache now
	42	parent unable to contact family child
	43	parent improving, X had good sleep but a lot of ear pain, nurse said put warm cloth on ear, instead of regular Tylenol give Tylenol with Codeine, I am reluctant to give until bedtime, we are not kind of people who take pills, feel weird giving pills q4h, X doesn't complain so maybe doesn't need it (<i>writer spoke about different ways children express pain</i>) child pretty good, ear pain always there, drinking 4 cups no tummy ache or fever.
	44	parent X perkier, until 230 pm, down again, not talking, drinking little more than 1 cup/day, no fever bleeding, slept up to drink during night. child
	45	parent X screaming today with sore throat, no sore tummy, not eating anything, drinking apple juice few spoonfuls, eating 1 piece canned fruit, no fever child, good, (<i>went over pain cycle encouraged child to set daily fluid and food goal</i>)
	46	parent X drinking apple juice, eating 1 piece canned fruit, more pain today, didn't expect it, no fever child slept through night, throat hurts a bit, ears don't hurt, drinking apple juice, water and gingerale about 1/2 glass/day (<i>went over pain cycle encouraged child to set daily fluid and food goals</i>)

Day 5

18). How are things going so far for you ... in caring for (X)?

Day	Case	Parent Response to Questionnaire Items
5	01	good, went out for groceries, things getting back to normal routine
	02	very well, pretty much back to normal
	03	good so far, X is still pale, is this normal?
	04	ok for us, mom back to work
	05	I was up all night, X's sister very ill, I worked today, I have 3 kids with chicken pox, hectic, I have a lot of energy, used to this, have baby-sitter who comes to house when working
	06	when kids sick, act babyish
	07	fine, good
	08	good, X seems to be doing better today
	09	X was fine today, now grumpy
	10	fine

Day	Case	Parent Response to Questionnaire Item
5	11	really good today, going very well, no concerns, progressing very well, pleased
	12	I have a cold now, hope I don't give it to kids
	13	mom not in
	14	I haven't been home today, my mom is with X, X is irritable, grumpy with me, pretty hard to have X in the house, home with X tomorrow, I had to work, X takes it out on grandmother and me
	15	good, no questions
	16	ok
	17	good, fine
	18	great
	19	not too bad, just resting
	20	good, my kids upstairs all day they haven't been home all weekend, I am catching up on my sleep and housework

Day	Case	Parent Response to Questionnaire Item
5	21	family not in
	22	family out until late
	23	good
	24	pretty good
	25	good, when can X start eating solids?
	26	good, X not home all day, X with biological father, they were in and out of my office, a lot of people don't understand, they think I am overprotective
	27	unable to contact family
	28	good
	29	I went out last night, everything good
	30	now have to watch X, have to call X back, X wants to go outside

Day	Case	Parent Response to Questionnaire Item
5	31	ok, concerned about X's ears, hurting, no drainage, told X not to get ears wet in pool
	32	really bad night, we went 1/2 way to hospital, decided to go back home, X seemed ok, X was afraid to go back to hospital, asked if they would cut open, last night had blood around rim of mouth, told nurses, forgot to tell Dr., I am aware every circumstance is different, husband rarely at home, hard on me, X had an apple last night, chewed it up really well, do you think this triggered it?, I am at a loss as to what to give him, don't know if I can go through this again, Dr. advises 3 year old also have T&A, I can't do it anymore, I suggest a list of food for home use
	33	doing better, relief to see X perky, X is feeling optimistic today, blessing for us to have your daily phone calls, they are supportive
	34	mom golfing today
	35	nanny busy
	36	good, X complaining of pain in throat, to be expected though I guess
	37	good, sorry about not being home, friend in hospital, I have been with friend all the time, want to take X to family Dr. to make sure no infection, for my benefit more
	38	really good, X a lot improved, smiling lots, talking ++, eating better
	39	pretty good, X not taking Tylenol all day
	40	pretty good, I'm worried about ear ache, no fever

Day	Case	Parent Response to Questionnaire Item
5	41	mom not in, working
	42	not bad, took X to see Dr. today, pain yesterday night and today was worse than after surgery, Dr. checked ear said ok, Dr. suggested gargle with baking soda and water (<i>mom asked if this ok, writer referred mom to inform sheet</i>), X wants my full attention I feel guilty cooking for rest of family when X can't eat
	43	fine, waiting for pain to go away
	44	up and down, I'm concerned about urine, thick looking (<i>writer suggested could be due to lack of fluids, Tylenol suppositories, urinalysis?</i>)
	45	very hard for me, both of them, I'm tired, I'm scared something happen to X, they won't listen to me
	46	as above

Day 5

19). How are things going for (X) ... so far?

Day	Case	Parent/Child Responses to Questionnaire Item
5	01	parent: X doing fine, ate pizza, fruit, plums, not having too much liquids, have to really encourage X, slept well child: good, not that good, really hurts, had pizza, crazy bread, slept
	02	parent: very good, best day, not complained, X doing very well, still not same with fluids, still not as much as normal, slept at grandmas, slept through night. Why do I need to keep X indoors for 1 week, and how long before can blow nose?" child good as new, no ear ache
	03	parent child feel good today, throat ok, doesn't hurt, still feels like a lump but hardly, drinking ok, still hurts when swallow, drinking a lot more, slept well
	04	parent X went to grandma's today, seems to be doing well child good, pretty good, no ear ache, slept through night, drank 3 cups water, appetite good
	05	parent X has ear ache, headache, saw family Dr. today, has chicken pox, no fever, feels better after Tylenol, appetite increasing, fluids good, woke up at twice last night, crying of ear ache, have fan going to cool X child ears hurt, throat not too bad, little bit of headache
	06	parent X doing better, not eating much, no change really, talking more, ear ache this am, drinking what I give, slept well every night child good, still hurt when swallowing, ears still hurt, had ear ache this am, tummy ok, drinking lots"
	07	parent X getting better every day, medication every 4 hr., bleed a bit today, spit out a bit, should I be worried?, has ear ache and sore throat, slept through night, not drinking as much as should, not eating much, no appetite child still hurts ears, throat better, drinking ok
	08	parent X doing better, still laying in bed child already today a bit better, throat and ears hurt, throat hurts more, drinking a lot, eating soft foods not too much, still a bit dizzy when get up, slept well
	09	parent no medication today, X not taking it, had soup, juice fluids ok, tired, overtired, cranky now waiting for me, no fever, no stomach ache, slept well until 5 am then started to cry, not taking medication until really needs it, just won't take it, I try
	10	parent no stomach ache, X slept well last night, diet ok child good, slept well, ate cookie, ears don't really hurt, throat kind of hurts

Day	Case	Parent/Child Responses to Questionnaire Item
5	11	parent appetite increasing, X feeling better, playing with next door kids, taking fluids on own, had nightmare last night, did not wake up with sore throat, no ear aches
	12	parent X seems to be fine, eating all, drinking well, no Tylenol last night, brushing teeth, voice a little still, otherwise perfectly normal, riding bike, sleeping fine child out riding bike
	13	parent mom not in child throat sore this am, eating a bit better, no ear ache, slept like a baby

	14	parent X felt nauseated yesterday, getting sick on Tylenol, X is not use to having pain for so long, not prepared, I think that is why so irritable child really sore today, ears started to hurt today, no tummy ache, no vomiting, medication helping a little only for a little while, slept pretty good last night, drinking 1 glass/hr
	15	parent X fine today, a little pain, not getting Tylenol, drinking good, drinking more, eating hamburger and fries, slept through night child good, a bit sore when swallowing, no tummy ache, no ear ache
	16	parent X had really bad ear ache this am, throat sore, taking fluids not too badly, still hard to take food child ears hurt both, throat sore, eating hungry <i>suggested warm cloth to ears</i>
	17	parent mornings not very good, X had dry throat especially, slept through night, no fever, no upset stomach child ok, throat sore this am, lot better later, ears kind of hurt (both), jaw hurts, drinking not very much (3 glasses/day)
	18	parent X doing good, ears a little sore, other than that doing very well, eating good, taking lots of fluids, no fever, no upset stomach, sleeping through night child at aunts house
	19	parent X much better today, out of hospital yesterday, hospitalized 2 nights, infection over, back of throat white, taking fluids very well, diet soft, no fever, slept well last night, grouchy
	20	parent slept good last night, eating reasonably, good fluids, no fever

Day	Case	Parent/Child Responses to Questionnaire Item
5	21	parent not too bad, X went down town, ate soft taco, Arby sandwich, soup, milk shake, gradually increasing food, not drinking as much as should, no fever, no stomach ache
	22	parent family out until late uncle: eating drinking good, coming along
	23	parent seems good day, X not complaining of ears or throat, eating quite a bit today, better, drinking very good now child good, ears and throat don't hurt, just when swallow
	24	parent X tired today, fine, eating drinking good, slept through night, no long sleep, wakes up throat hurting, had tummy ache today, no fever, had huge supper, soft food child good, enjoy self
	25	parent not been on Tylenol since yesterday, drinking good, wants solid food, no stomach ache, no ear ache, sleeping through night child fine, no throat ear ache, not hurting in am
	26	parent X's diet improving, drinking well. Since you talked with X, throat improving since that time, what do people do, I am not a bigot but people who don't care for kids, what happens to the kids, I'm looking at this from social worker perspective, kids may not get care they need, has our local government looked at this, don't know what home environment is, Dr's don't make home visits, don't know if kids looked after well, kids should stay in longer child how come my tongue hurts?, drinking good, eating
	27	parent child
	28	parent X not bad this am, no breakfast, ate after Tylenol, drinking well, no fever, slept well child good, ears hurt
	29	parent family not in tonight

		child
	30	parent X talks with mouth full of saliva reluctant to swallow it, feels energized, wants to play, have to keep encouraging fluids, had soup, slept through night, no tummy ache child throat way better, drinking good, eat better, voice sounds better, ears don't hurt

Day	Case	Parent/Child Responses to Questionnaire Item
5	31	parent X pretty sore today, scabs ready to come off, spit something out, no evidence of fresh blood, drinking ok, tough today, no fever, stomach ache, no ear ache, slept through night child pretty good, getting pretty sore, scabs coming off, eating soup
	32	parent X woke up shaky and sobbing, took only 1/2 cup fluids all day, we took X to hospital, dad in with X now, really hard having X home, feel like I am ready to crack up, really hard to cope now, it is very hard to bring them home, nurse said "you will have to be mean" I was not very impressed, its hard to take on their role, I'm trying my best, I also have 3 year old, hard to have sick child and have child who is very demanding, makes it very difficult, its been a rough day, they said X temperature was normal at hospital
	33	parent X perked up today, 13 hr sleep, purposefully didn't waken, seems to be on mend, 4 glasses fluids, nose cleared out child a lot better, better than yesterday, had 13 hr sleep, can breath better, drinking 4 glasses, ears don't hurt
	34	parent mom golfing child much better, nose all cleared up, no chest pain, throat still a bit sore, up on feet and stuff, drinking ok, eating more,
	35	parent nanny busy child good, better today, no pain, pain a lot in am, out a bit today
	36	parent X drinking quite a bit, more than 2 cups, no bleeding nor stomach ache. Child throat a little sore, ears hurt a little, drinking 2 cups/day, ate hamburger and fries
	37	parent X eating just about everything, rinsing mouth, had a bit of fever, good appetite, wants to eat everything, outside without coat and shoes (raining) hard for X to understand, will take to family Dr. to make sure no infection child good, throat doesn't hurt, ears hurt now, slept well, no bleeding, drinking 5 glass's/day, not hot
	38	parent X drinking ++, 6-7 glasses/day, eating ++, appetite good, still sore throat, no bleeding, no coughing, no fever, up once early am, sleeping well, getting more sleep, give Tylenol when X needs it, no tummy ache child fine, a whole bunch better, eating pancakes, no ear ache, pain only when chew
	39	parent X drinking as much as able, no fever, tummy ache, bleeding or discharge from ears, no ear ache, neck a bit sore, no headache, not much appetite, not hungry child good, throat hurts a bit, more in am
	40	parent X has no fever or discharge from ears/throat/nose, no tummy ache, hungry, tried to eat solid foods, sleeping ok, makes real effort to drink child ok now, throat hurts a lot in am, headache and ear ache, Tylenol #2 helped, how long until pain stops?

Day	Case	Parent/Child Responses to Questionnaire Item
5	41	parent mom not in child fine, better today, ears hurt a bit, nose plugged a bit, no fever, 3-4 glasses of water/day, ate custard, no appetite
	42	parent X not taking medicine, not eating anything, drinking 4 glasses/day, no fever, nor bleeding child sleeping
	43	parent X slept all afternoon, medications helped ear pain, having supper, slept through night, no oozing, throat white, no fever child medication help ear/throat pain, drinking 4 glasses/day
	44	parent family not in child
	45	parent X not eating or drinking anything, dizzy, total 2 oz today, not taking Tylenol, only Gravol (given once today), no fever, mucous throat coughed up some little blood in it child good, drinking
	46	parent X has pain in ears, had some canned fruit child good, drinking 1/2 cup/hr, ears hurt

Day 6

21). How are things going so far for you ... in caring for (X)?

Day	Case	Parent Responses to Questionnaire Items
6	1	I went to green house, getting my plants, great day
	2	really well, a bit concerned about X complaining of nausea today and X's appetite is not as it use to be, no longer giving X Tylenol, is on antibiotic writer <i>suggested antibiotic may be giving X GI upset</i>
	3	ok today, X has appointment with Dr. tomorrow
	04	ok, X had a rough night, taking tomorrow off to encourage X to drink and monitor, I phoned surgeon this am, concerned why X all of a sudden hurting when X was doing great, didn't expect that
	05	awful, unreal, I have a bad headache
	06	yesterday 240 am X awoke crying with ear ache, gave X Tylenol, back to sleep, had ear ache today, surprised hurt 3 or 4 days after - does this happen?, X not eating much at all, worried about this, throat white - normal?
	07	X is still complaining of a lot of pain, had a bit of bleeding yesterday and today mixed with mucous, not too much, must have scratched throat, poor appetite, won't eat, drinks only when I force, wondering why X is still having pain like this
	08	I am not in pain, X still is though, I have 2 questions: should X have ear ache now? X has very foul breath, should I expect this?, I am glad you talked with X yesterday about eating, X won't with me, is eating a bit better today
	09	dad: not bad, X should have stayed in hospital a couple of days, 1st couple of days trying to convince X to drink and get routine going, doing fine, however, I expected it to go away by now
	10	fine, everything going fine, not much change from yesterday

Day	Case	Parent Responses to Questionnaire Items
6	11	great, because X is doing well, no questions
	12	getting over a cold
	13	no questions
	14	I wish X were in hospital, trying to make soft diet, X is very irritable, crank, better they try to feed X, thought by now would be mending, X is miserable, I'm stuck between a rock and a hard place, I can't leave X alone and I have to, X is mad at me for leaving, my mom helps, I'm finding it to be more difficult as days go by, I don't think its fair of Kline and cut backs, X should be in hospital 5 days, this is not minor surgery
	15	fine, not doing anything different from what I normally do, going better than I anticipated
	16	good today
	17	mom and dad not in
	18	no questions
	19	well rested. Glad over with
	20	good

Day	Case	Parent Responses to Questionnaire Items
6	21	family not in
	22	X doubling up on Tylenol, is X immune to antibiotics?, X covers hands over both ears, I would have thought by now X would have been better, this bothers me the most
	23	good
	24	not bad, X not having a great day
	25	really good, I feel like I am getting cold
	26	holidays
	27	unable to contact family
	28	good, frightening last night, X crying for 1/2 hour last night, took X in today with piercing ear pain, last night tough, wouldn't stop crying, at hospital says no infection
	29	everything good
	30	today ok, yesterday worried X had infection, pain almost as bad as first day, gave Tylenol and put X to bed, improved slept, X is getting frustrated with not being able to eat solids and with my diet selection

Day	Case	Parent Responses to Questionnaire Items
6	31	ok, I am concerned about ears hurting, X has no drainage, I told X to stay out of pool not get ears wet
	32	parents not in
	33	I went golfing nice break, stressful for me
	34	good, not much care to do, X is responsible, went to see surgeon for early visit
	35	good, yesterday I was not feeling well, keep self busy, so no pain for me
	36	unable to contact family
	37	good, a bit of pain when X eats, throat really sore, surprised not better yet, other 2 kids better, hard to make X drink hard to keep X in, will take to Dr. tomorrow. X wakes up crying, will try Tylenol with Codeine
	38	bad night last night, X had pain ++ in ears hurt a lot, throat hurt crying at night, Tylenol and sips helped, how long does it take for them to recover?, thought it would be better by now, seems the other way, does X have infection? Will take X to see family Dr. tomorrow
	39	not too bad, X has lots of pain this am, due to french fries? Mouth sore can't open wide, went to park 1/2 hr, felt better outdoors
	40	pretty good, mom went back to work, felt comfortable about this

Day	Case	Parent Responses to Questionnaire Items
6	41	parents not in
	42	unable to contact family
	43	unable to contact family
	44	unable to contact family
	45	X still not drinking, eating, take to pediatrician, says ok
	46	X drinks better but not much, give me hard time

Day 6

22). How are things going for (X) ... so far?

Day	Case	Parent/ Child Responses to Questionnaire Items
6	1	parent X slept from 9pm-9am, good sleep, good day so far, X eating better (taco chips), fluids ok, still needs encouragement to drink, child throat feels better
	2	parent X back to old self, no complaints of pain, playing like use to, eating soft diet, felt nauseated earlier child out playing
	3	parent X taking soup and fluids, slept well, all night, no tummy ache child good, just the same hurts when swallow, of and off hurts, yesterday when called it didn't hurt at all, then 2 hr. later it hurt just like the first day why??, I see Dr. tomorrow I guess I will see what he says
	4	parent in a lot of pain yesterday for ears, Tylenol all night, phoned surgeon said referred pain, seeing Thursday, suggested up dose of Tylenol, not drinking that much, more pain with ears today, very tired last night, X generally more active, today hot, didn't drink, dehydrated, will take tomorrow off to get X to drink, monitor X, X told me took Tylenol today and drank a lot, checked with baby-sitter who said X didn't have any Tylenol or fluids child feeling good, still hurts when swallow, slept but ears hurt a lot, eating ok
	5	parent took X to hospital, X had headache earache, screaming of pain when X woke up, checked for meningitis, Dr. in emergency told us to stop Tylenol with Codeine, put on Tylenol plain instead, told us to give when X needs it, use blow dryer for ear ache, I called surgeon called about ear ache, said it was referred pain, use hot water bottle, blow dryer, still bad ear ache, surgeon will see next wk, little temp child went to hospital, headache feel better now
	6	parent not in child throat much better, ear hurt a little bit, appetite getting bit better, no tummy ache, slept all night
	7	parent X says in a lot of pain, wants pills q3-4 h is X exaggerating??, getting hooked??, now wants one, I gave X extra strength, I think X needs something a bit stronger right from start, X is just constantly taking the Tylenol and not eating (writer suggested mom contact Dr. to obtain alternative analgesic) child better throat, ears hurt a bit, slept through night, ate noodles, drinking milk gingerale
	8	parent X has no temp today, last night temp 100, X is still complaining of sore throat/ears, still not eating well but better, drinking only if we push child fine, slept well, sore in am, still sore all the time, ears hurt, drinking couple glasses/day, eating a bit more
	9	parent X was up for most of day, still pretty sore, drinking fine, appetite still poor, woke up at 3 am, no vomiting nor tummy ache, no ear ache, should have stayed in hospital a couple of days, 1st couple of days trying to convince X to drink, get routine going, doing fine, expected it to go away by now, tongue white child
	10	parent X doing a bit better today, eating drinking, no tummy ear ache, slept well last night, eating more today child good, making a hotdog, really good throat, no earache,

Day	Case	Parent/ Child Responses to Questionnaire Items
6	11	parent X much better, more self activity, eating, sleeping well last night, intake of fluids good, played outside child
	12	parent jaws hurt X more than anything, slept well, no stomach ache child
	13	parent coming down, X doing well, had hot dog, soft foods, is hungry, child throat very sore in am, medication better, no ear ache, eating a bit better, slept well
	14	parent taking X to Dr. tonight, X not eating or cooperating, cranky, taking medication round clock, not helping, might have infection in throat, slept through night, taking Gravol, drinking lots, no bleeding, ear ache all the time child throat very sore, ears very sore too, ran out of Tylenol #2,
	15	parent X eating perfectly normal, slept child doing very well, no ear ache, hurts only when swallow
	16	parent good, X slept through night, eating a bit more, fluids good child good, throat still sore getting better, ear ache this am
	17	parent mom not in child throat really sore both ears really bad in am, slight headache now, drinking 1/2 cup/hr, has to push self to eat, when will I feel better?
	18	parent good, really good, X baby-sitting today, drinking more child
	19	parent X slept well, eating soft foods, drinking quite a bit, no fever child
	20	parent good, X a little whinny, not getting enough sleep, don't know what time X fell asleep, didn't eat this am, drinking lots, no fever tummy ache nor ear ache child up late, throat hurts when swallow, ears don't hurt

Day	Case	Parent/ Child Responses to Questionnaire Items
6	21	parent X eating soft diet now, child
	22	parent ear bothering X a lot again, puts hand on it, has a temp, giving Tempra, drinking 1/2 glass/hr child ok, ears hurt
	23	parent doing fine, X went for a ride today, slept a couple times, crying had night mare, drinking good, eating improved child no pain in throat or ears, eating and drinking
	24	parent X was tired had sore throat, went a bit too long without Tylenol, quite tired, throat quite sore, not as bright as yesterday, not sleeping as well had bad dream, felt sick to stomach, drinking well, no fever child good, sore throat, drinking
	25	parent really good, X drinking well, appetite back, no nausea or vomiting, slept good child
	26	family on holidays
	27	unable to contact family
	28	parent no fever, last night 99, X drinking perfect, eating well, no nausea child rough night, ear pain woke me up, know why pain in ear, feel better now, still hurts
	29	parent X ate more today, got meat, slept well, drinking normal amount, drank

		from straw yesterday - no damage, no fresh bleeding, back of throat looks white and gross, no fever, tummy ache, back to normal self child rested watched movie, eating really well, drinking really well, no tummy aches, helped mom clean house, throat feels very good
	30	parent X drinking quite good, appetite good, hungry, ear pain, no nausea, no fever nor fresh blood, child good today, throat hurt when swallowing not that much, last night had really sore thought of other things, medicine helped to, drinking good

Day	Case	Parent/ Child Responses to Questionnaire Items
6	31	parent X starting to have ear ache, lays on it for relief, scabs starting to fall off, yesterday was tough had pain, no spitting up, coughs, no fever, trying to take couple glasses fluids/day, eating more, up 430 needed medicine child ears hurt right one just a bit, throat ok still hurts to swallow (explained referred pain)
	32	parent X a little bit better, still in a bit of pain child good pretty good, drinking ice tea and water
	33	parent ears hurt X now, no Tylenol yet, spunkier ate macaroni, nauseated at night (erythromycin) 3-4 glasses fluids/day, on fever, fairly weak, child good, tasted macaroni, have ear pain
	34	parent slept through, no fever child better, throat still hurts, taking fluids ++, eating more, ears not sore
	35	parent 4 glasses fluids/day, no temp/bleeding, X eating normal now, sleeping well child good, better today, tired, ears not sore, tummy not sore, sleeping well, out to mall
	36	unable to contact family
	37	parent give X medication as needed, no fever, throwing up nausea, up 330 am crying gave Tylenol, 4 glasses fluids/day, no ear ache child good, went out today, throat ache in am and now, not throwing up, not spitting blood up, not feeling hungry
	38	parent X slept quite a bit today, drinking quite a bit, both ears hurt, fever this am, Tylenol this am, no discharge ears/mouth, no spitting up, not much food child fine, not very good am, ears really hurt, went out to movie last night
	39	parent X chipper, fluids 4 glasses/day, no fever spitting up bleeding child good, ears ok, throat hurting
	40	parent X in better spirits, no complaints of pain, no ear ache, fever, slept well, fluids ok child throat hurt a little especially swallowing in am

Day	Case	Parent/ Child Responses to Questionnaire Items
6	41	parent mom not in child throat good, ears hurt lots last night, not sleeping, Tylenol effective short periods, no fever, drinking 5 cups/day, eating vegetables boiled
	42	parent family not in child
	43	parent family not in child
	44	parent family not in child
	45	parent family not in child
	46	parent family not in child

Day 7

24). How are things going do far for you ... in caring for (X)?

25). How are things going for (X) ... so far?

Day	Case	Parent/ Child Responses to Questionnaire Items
7	01	24. child had nap earlier, looks pale now, X went for bike ride to play ground, about 10 minutes ago, X started saying throat really hurts, I'm surprised X is hurting now, didn't expect it, X is also feeling feverish and crying 25. parent, X has sore throat, really really hurts all of a sudden, gave Tylenol, no signs of bleeding, back of throat looks good, slept well last night, mom distracted repeatedly saying child is hurting, writer suggested mom contact # on inform provided, will check with mom tomorrow child, throat really hurts with and without swallowing, no tummy/ear ache
	02	24. X had ear ache today, mom working, is it normal for throat to look white?? 25. parent, X has ear ache, headache, spit up a bit of blood, red mixed with saliva, not much, if happens again will call Dr., X says it hurts eating ice cream child, good sort of, spit up a little blood, sneezed after, ears hurt today, hurt every single day, toothache, stomach ache, drinking, slept through night
	03	24. X is complaining of pain a bit, didn't make it to see Dr., no car 25. parent, X slept well child, slept, still hurts when swallowing
	04	24, good, stayed home from work, took X to Dr. 25 parent, X is still uncomfortable, getting to eat/drink more, being firm, ears in pain still taking Tylenol, to see surgeon tomorrow, no tummy ache, not spitting up blood, slept through night, up to take Tylenol child, throat feels scratchy, not too good, hurt when swallowing
	05	24, pretty good, sleeping with me, throat sore when awake 25, parent, X has had 3 major ear aches, used blow dryer, put cotton balls in ears, no Tylenol at all, better now, intake of fluids good, a bit of blood child, stayed up, ears hurt, drinking lots, not itchy, eating alpha getti
	06	24, finished antibiotic, eating no ear ache 25 parent, X fine now, last night awoke me crying with ear ache at 320 am, child, good today, didn't sleep well after ear ache, medicine helped, drinking lots, still hurts to swallow
	07	24. Things ok, went to work today 25, parent X seems to be better, still in pain but not complaining as much, appetite bit better, have to push fluids, awake once last night with ear ache child, good, both ears better now, sort of eating, drinking gingerale, milk
	08	24, fine 25 parent, X better today, was up and dressed child, throat seems better, ear ache earlier on now ok, drinking as much as I can, appetite still not good
	09	24, not too bad, long day 25 parent, X was up all night, crying with ear ache, still drinking good, problem still with eating, no fever nor tummy ache
	10	24, good, everything fine 25, parent X is doing all right, coughed up chunks of red stuff, told X not to cough, no more, drinking lots, eating really good, slept well, woke to give medicine

Day	Case	Parent/ Child Responses to Questionnaire Items
7	11	24, great 25, parent , X at grandma's, doing really well, throat good, eating and drinking more, sleeping through night, no vomiting.
	12	24, ok 25, parent , jaw still hurts today, X slept well
	13	24, pretty good 25, parent X getting better a bit sore when swallows a little, eating good, drinking lots of water, slept
	14	24, X better today, after taking to Dr., X smartened up, I told X not to dump all on me, started to realize world didn't revolve around X, life goes on, got some medication, special foods (apple food cake, potatoes), Dr. told X, X has to eat, I slept with X, yesterday tumultuous 25, parent , Dr. said throat looks good, no throat infections, after X being told by him X realized X was unreasonable, live with it, deal with it, slept well, feels hot (no thermometer), slept today
	15	24, good, tonsils white, normal?? 25, parent , fabulous, X did really well, drinking good, sleeping good, ears don't hurt child , no pain in throat or ears, eating and drinking, back to normal
	16	24, good 25, parent , good, X had ear ache today, 1/2 bowl chicken soup, very good fluids, no stomach ache, no fever child , good, throat same as yesterday, ear ache comes and goes, drinking at least 1/4 cup/hr
	17	24, pretty good 25, parent , X took analgesic middle of night, eating more solids, fine with fluids, visiting friends child , ok, visiting, throat less sore, lost 5 lb.,
	18	24, good really good, 25, parent , healing and pain seem to take longer than we thought child , throat getting better, still hurts, not healed all way, ears really hurt, woke up with ear ache, not eating solids yet
	19	24, ok 25, parent , X slept well last night
	20	24, good, I'm worried about X not eating, at daycare today 25, parent , diet mostly rice and ravioli, X eating cookies however, not drinking as much, woke up crying last night complaining of throat pain, a little tummy ache child , good, throat hurt today, when had peanut butter sandwich, 3 glasses water

Day	Case	Parent/ Child Responses to Questionnaire Items
7	21	24, ok 25, parent , X had soft diet, had stomach ache felt like throwing up, had gingerale, settled down, had rash from pills, fluids ok, not taking any pain killers since discharge, X doesn't show pain, very quiet this am, spit up old mucous blood, schedule to see Dr. next wk, child , good, throat hurt this am, ears don't hurt
	22	24, fine 25, parent , X just fine, eating something, drinking fine, X was agitated

		yesterday, better today, ears still really hurting, other than that seems to be picking up child , good, ears don't hurt, throat hurts
	23	24, good 25, parent , X complaining of ear and jaw pain part of day, no fever, had stomach ache last night, drinking well, eating good, hungry, not eating what X wants, not spitting anything up, said something tastes awful in back of throat, didn't know can bleed up to 14 days after surgery child , throat good, ears hurt once today, drank big bottle of pop
	24	24, good 25, parent , X tired again today, pain a lot better today, slept through night, takes a while to fall asleep, diet not too bad, less than usual, good fluids, had small tummy ache in am, no ear ache, throat hurt in am, another headache today, child , good, headache gone now, had soup liked it
	25	24, unable to contact mom until 8th day, report follows: good, 25, parent , X went to see Dr., X had throat infection, feels better since on Amoxil, child , fine, throat sore, looks swollen and feels like a cut, doesn't feel hot,
	26	family on holiday
	27	unable to contact family
	28	24. no one mentioned scabs falling off today, shock, woke up at 130 am, ear pain irritable, went to hospital in afternoon, no infection throat ears, called surgeon, says unlikely (infection) 25. parent X like this all day, spit up white things, no blood, Tylenol q3-4h today, hard time eating drinking like the 1st day, couple glasses today, low fever 99 child , scratched ear with nail, woke up with pain, medicine makes it better, both ears hurt
	29	24. not too bad, yesterday up at 1230 am, sore throat, hitting self, not himself, crying, gave Tylenol, fine now, when woke up looked rough not restful sleep 25. parent X felt warm this afternoon, with Tylenol better, pushed fluids today, not spitting up, no bleeding, eating pancakes, scrambled eggs, mashed potatoes child , good, helped mom today, hurts to drink, ears hurt
	30	24. good, no problem, only problem is feeding X, X wants to eat different things, don't know what to give X 25. parent X bored with not being able to ride bike swim, drinking ++, sleeping pretty good, no fever, no ear aches child , good, hurts in am a little, bananas hurt my throat

Day	Case	Parent/ Child Responses to Questionnaire Items
7	31	24. good 25. Parent pretty good, ears still hurt a bit, X drinking quite a bit, trying to eat, afraid X will make something bleed, no fever no spitting up child , pretty good, ears still sore, throat better, its how it should be, back of throat white appearance
	32	24. better, X saw Dr. today, says doing good 25. Parent hard time, X shakes from pain when medication wears off, drinking better, real problem eating, not getting enough food, quiet no fever, crying I am child , good, trying hard
	33	24. ok today, only concern X is hungry, hard to find something to feed X

		25. Parent X had trouble sleeping, getting to sleep was over tired, a bit of nausea, no fever child, throat and ear pain mainly, no vomiting, no tummy ache, appetite +
	34	24. X's brother called me at work, X was bleeding from mouth, it had stopped by time I got home, gushing out, amazingly cleaned up, scab came off, a one time thing, no problem now, X feels way better now, had not eaten anything, just got up and it happened 25. Parent X was up at 430 with severe pain, no fever, up now, taking fluids trying foods child, all right, tired, woke up at 430 real bad pain
	35	24. good, its good now 25. Parent X eating regular diet now, no fever, drinking really good (3 - 4 glasses/day), no throwing up, no spitting up less now, no tummy ache, slept child, good, eating really well, drinking good
	36	unable to contact family
	37	24. good, X feeling better today 25. Parent checked throat is white on one side and red on the other, no fever, up last night 230 pain gave Tylenol, ears and throat very sore at times, check with Dr. tomorrow to make sure child, good, up night hurt a lot, pill helped, not warm, no bleeding, 5 glasses/day
	38	24. better, took X to Dr., healing quite well, 25. Parent X had little ear discharge, got another prescription for Tylenol, they said 2 weeks, had really bad night, ear pain better now, nasal congestion better, drinking well, no fever spitting up, has been really good about handling it
	39	24. good, no severe pain 25. Parent X had 2 dishes ice cream, soup fish sticks, to see Dr. tomorrow, no fever bleeding or discharge from ears/nose/mouth, slept through night child, throat hurts in am, went to park, ate fish sticks soup, drinking lots, ears don't hurt
	40	24. really difficult, I'm back to work yesterday, X in tears really sore, wants me home, X is tired of being sick, I took time off work to be with X 25. Parent X drinking about 1 liter fluids/day, no fever tummy ache, sleeps through night, no bleeding, ears hurt especially in am child, in am my pain worse, thanks for phoning me

Day	Case	Parent/ Child Responses to Questionnaire Items
7	41	24, pretty good 25 parent, taking fluids & food, no fever, not spitting anything up child, pretty good, better, slept ok,
	42	family not in
	43	parents holidays
	44	family not in
	45	family not in
	46	family not in

Day 7

27. Did you receive any information from doctor's, nurses or other staff that you found to be inconsistent with (or different from) what you have experienced at home in this past week?
28. Were there were any issues or problems about caring for children at home following day surgery which we did not ask you ... but which you feel are important?
30. adverse: child admitted to hospital
child taken to emergency
child taken to medical walk in clinic/center
child taken to surgeon/family Dr. earlier than scheduled follow-up appointment

Case	Parent Responses to Questionnaire Items
01	27. exceptional, I have no complaints, I found them wonderful, all of them, nurses never left us alone 28. I am optimistic self sufficient, just get on with it, if problem get to hospital, all bases were covered, they covered 100% before we left (medication, important things bleeding, feel free to talk, Dr. great, feel strongly went well, I don't take this lightly it is a T&A, we are in good hands, Dr./hospital, in comparison to other individuals (kids with cerebral palsy, accidents) relative to that, this is minor, appreciate you chose us to participate in study. 30. on 5th day mom took child to emergency (because child had intense throat pain, felt feverish and crying, no bleeding), emergency too busy so took to walk in medical center, assessed, scab irritation, mom had worked 5th day
02	27. rated an original 10 for accuracy 28. appreciate the follow-up, I told my mom that I was glad you would be calling every night just in case, they should have follow-up not just for study, we don't see Dr. for 1 month, so I think a few days follow-up is good, concerned that they should keep children in longer than 2 hr., they should keep in for at least 4 to 5 hr. I'm glad X is home with me but I was worried should have kept X overnight, especially since surgery was in afternoon, should have kept X, not have complaints but always what if.
03	27. rated at 10 for accuracy to original question 28. very worried about infection, if eating right, right medication 1st 2 days should be in hospital, at least 1st night, especially this surgery, X was drowsy and sick, atmosphere at home kids screaming (10 other children at home), not a good atmosphere for sick child, I didn't know what to expect hoped the Tylenol would work, gave Tylenol, X slept good, but don't know if Tylenol good, I know how to take care of my kids but still don't know for sure, don't have the knowledge for things that can go wrong, at hospital they get the rest and attention, at home too much noise, can't control things for their rest 30. child had appointment with surgeon that was canceled (pathology) mom had no car
04	27. unsure about drowsiness X had, should I be concerned about this? I was told X would be sleepy drowsy, I didn't expect totally passed out, didn't expect ear pain so severe, X rated pain low on scale but X would lay on floor crying even with Tylenol, wouldn't eat or drink, didn't expect X to be better and then worse few days later. 28. don't think so 30. mom phoned surgeon on 5th day, concerned why so much pain when X was doing so well, didn't expect that, mom taking tomorrow off to be with child
05	27. originally rated 10 for accuracy 28. wanted to make sure had all the information, with talking to you I am less worried. I don't agree that kids should be sent home after this operation at all, I disagree with this, they are too young, adults ok. I heard from others they have problem with their kids, I know it is with Alberta Health Care, they are letting kids out too quickly, my husband was in 4 days, too much responsibility on parents, its up to us to deal with anything, X scared us last time X had daysurgery, people not getting care anymore they should be getting, husband feels same

	way, dad didn't have patience when X cried and cried, I told him to take X to hospital, I don't know what we would have done if we didn't help each others. (mom and dad separated, take turns caring for children, mom works 2 jobs, has in home baby-sitter) 30. taken to family dr. on 4th day for ear and head ache, other kids have chicken pox, put on Tylenol with Codeine, on 5th day child taken to emergency had lumbar puncture done for headache, screaming in pain told to stop Tylenol with Codeine, on Tylenol now, mom phoned surgeon 5th day regarding ear pain, surgeon advised it was deferred pain will see X in 1 weeks time
06	28. better for children if they stay overnight in hospital, even if prepared, I would prefer this. Nurses know better, based on their experience. Its been exactly 1 week, finally eating etc., now happy, I don't have to worry now (mom asked if X needs to put cotton balls in ears when going out, her friend advised her of this)
07	27. rated this a 9 (inconsistency) later stated 3 or 4 people told me give children's Tylenol, nurses didn't write amount down, children's Tylenol didn't do trick, I didn't know 28. if I had known ahead of time X would have so much pain, thought X would have pain for day or 2, not prepared for that, didn't know that much about surgery, didn't see film, Dr. didn't explain, wasn't prepared recovery would be so long, no appetite, didn't bounce back as fast as I thought, had to cancel hockey camp, Dr. said X would bounce back, X didn't. Nurse told me unsafe for X to play hockey right after anyway, glad to have follow-up, appreciate it, things happen, nice to know getting phone calls 30. mom phoned unit on day 2 to get advise on what to do since child having intense pain rolling on floor refusing any medication, advised to give him Tylenol extra strength, on day 5 mom stated to me child still complaining of a lot of pain had bit of bleeding poor appetite and drinking only if forced, suggested mom contact Dr. to discuss ongoing discomfort etc.
08	27. mom stated she assumed no inconsistencies 28. surgery was on Friday, I was home on weekend, dad at home Monday and Tuesday, if parents working may be terrible, X threw up a lot, sent home too soon, nausea and vomiting too soon up, this may have contributed to ongoing nausea and dizziness, if no one there to help out difficult for home care, great idea day surgery, people need follow-up though, found follow-up helpful, nice to know some of my questions were answered and that things like sore ears normal 30. on 5th day mom stated I'm glad you talked to X yesterday about eating, X won't with me, X is eating a bit better today
09	27. told to push fluids, X had citrus fluids for 2 days straight, now has blisters all over mouth, should have milk or water don't know, information we got was verbal, if had written information would be OK, we had none, totally unprepared 28. normal people not knowledgeable about medication, we got most of our information from friends, wished to have better information about medication or what to expect and when. Should get more information about ear ache, what to expect and how to react to it, I was under impression that it would take 1 wk for recuperation now I learn it might take 3 weeks, average person doesn't know, we do. If prepared to send kids home after 4 hr. If kids had coughed ruptured their sutures would we know? would we know what to do, maybe wouldn't recognize problem until its too severe, don't care a damn about our local government, parents may not be prepared, kids won't listen to parents, maybe would listen to other people 30. dad took child to emergency 5th day at 5 am because ears draining not prepared for this, if kids going home after 4 hr. parents should have increased expectations and know how to react to this, no treatment given in emergency
10	27. no inconsistencies, 28. I remember when I had my tonsils out, getting sick in middle of night, still question what I will do if X gets sick or bleeds in middle of night, if X has a lot of pain, I worry about OR, no surgery is controlled, better for X being at home for that type of surgery, but for other types I don't know, because young kids scared to be in hospital, I can care for X, X has own things, not surrounded by strangers, I like idea

Case	Parent Responses to Questionnaire Items
21	27. pretty well went as they said, pain soreness etc. everything would have been ok if X didn't have abscess on head, it bothered X more than OR 28. I didn't realize they wanted us to stay in hospital all day, didn't realize they had to stay until X recovered from anesthesia they didn't say they are not to clear throat/cough for 3 days, didn't say anything about gargling. X had no complications, hard to say maybe X would have gotten more rest and fluids if stayed overnight, might have been more relaxed. 30. on day 2 mom took X to family Dr. for possible throat infection, swab taken (rural, family Dr. of family in city)
22	27. none 28. I worried, sooner have X at home, comfortable at home, X might sense being alone I think they should be kept in extra day (night) they let go too soon, if had IV then this may not have happened, founding working and this very hard, I don't get to sleep at all, have people to help me but X wants me, every time I move X wants to come with me. X still has lot of pain, reason why X needed to be in more, should have kept X at least 24 hr, kept thinking if X were on IV it may have prevented the readmission 30. on 1st day child admitted to hospital, had ear and throat infection, blood clot in throat
23	26. 6 prepared, 28. worried, now nothing, general pain and all that stuff, having home is fine no problem in taking care of X. Work at home, child so proud to be involved in this study, X looked forward to the phone call every day, it made X feel big
24	27. no everything that happened to X - I expected, little things like headache tummy ache, uncertain about this, I find X gets headache if X hasn't eaten 28. X has sensitive stomach can't keep fluids down, worry about hemorrhage, up at 430 am most of night. Initially I would have liked to have X admitted but because X did so well I was happy to have X home but I was nervous (what if X hemorrhaged) X slept with me 1st 2 nights so I could keep eye on
25	27. would have liked more information about Tylenol not comfortable about Tylenol #1, said X would be up and about, but X had more intense pain than what I had thought, hard to take. Worried if bleeding, if problem with Tylenol, don't have car worry at night if something happens and no car, hard not having car especially with this Dr. told me in 1 to 2 days X would be eating, still not eating seven days later 28. should keep in at least 1 night, I was apprehensive 1st night, had no car for emergency, talked to nursing 30. on 7th day child woke up shaky, dizzy nauseated, pain, seen by family Dr. put on antibiotic
26	27. not prepared didn't know what to expect, didn't know what hotel had, they don't have what I needed, once home a 5, not expecting to deal with this, I was overprotective. I worried, first time had to do this, was in hotel, "terrible" they push kids out, like receiving line you are on conveyer but they tell you have 4 hr. you are concerned about your child, but its just terrible they should still keep in over night until sure no bleeding. I feel not enough information, didn't tell me X would be throwing up and to watch for dehydration 28. what do other parents do in different situations, scared for those kids, talking about health of children, should be screening for kids at risk, health and welfare of children should be over not saving money, kids dependent. As parent, I think personally I wanted to take pain away, I felt lost, I have never gone through this, didn't get right information, I'm always questioning information people give me, you are just a #. So when X tells me X has pain, I don't know if what X is experiencing is normal or not, is pain in tongue normal? I appreciate your help, I don't know where I would have been. Tremendous follow-up phone calls, should be for everybody, as lay person don't know, information what to anticipate and giving support
27	

28	27. maybe because everything so quick, was not pleased with it, our nurse didn't tell us anything gave us a paper written information, didn't speak with Dr. at all upset with lack of information maybe because we got in on cancellation. I worried because of X's vomiting, gagging uvula swollen hanging on back of tongue, still having problems. I got a sheet about NPO before surgery, didn't get any information about how to prepare for caring for X, at daysurgery told us a bit had to run around like crazy, had to stay in Edmonton for 24 hr., hard on me, I didn't sleep, military gave us a house if I had to stay in hotel I would have gone crazy. We had nurse that hardly talked, so no comment on verbal information. I was really upset, I phoned my sister about the ear pain, she told me the scabs fall off on 5th day, should have told us that, don't know normal expectations, X had extreme pain yesterday and today, never expected boom ear pain, I threatened X so would eat/drink, didn't know how to get X to do it. 28. honestly think I would have liked X to stay a day or 2. would have paid money to have X stay 1 week until shedding went away, should be longer than 6 hours, consider this ridiculous, if I would have known about this 5 day thing, paper information not sufficient, I got information from listening to nurses talk to other patients, even when I contacted Dr. it was not even good, sheet didn't say much about diet, 30. mom took child to hospital on 5th and 6th day, awoke crying with piercing ear pain, wouldn't stop crying, mom also called surgeon on 6th day
29	27. don't remember inconsistencies, nurses gave different inform to different parents 28. I worried if I didn't have someone to help me when I run out of things, single mom if no one with me definitely a 1, my mom stayed with us, lots of information from friends, nurses DR's didn't suggest anything like friends. I would have preferred consistent information. would prefer to know how to prepare X, I didn't want to scare X, didn't tell X much, X would get tonsils out and would have some pain, nice if had a food list, preferred X at home, happy to have X, more comforting for X in own surroundings, in our home I felt more comfortable, parents should be able to administer Tylenol, what I expected and what X did was two different things, it turned out good. when X came out of anesthetic asked me if X was really sick, if X was going to die. My child needed reassurance. They should ask parents if they would like nurse to phone for follow-up to check up, these phone calls were helpful, reassuring, although nurse calls 1st day, it is not enough, should call more frequently
30	27. Dr. himself said X will be well that it would be no big deal, however, my child didn't recover as fast as the Dr. said 28. if child has fever and don't know what to do, may not get much help, for X's brother I phoned a friend after 8 days, with X not much problem, in case where kids have more problems then should stay in hospital 1 or 2 days.

Case	Parent Responses to Questionnaire Items
31	27. pretty consistent 28. no
32	27. nurses said not to give ice-cream but handouts say give milkshakes 28. at first I worried if anything happened, concerned about X's heart condition & coming out of anesthesia. Staff should have talked to me like you are now, no contact with nurses, paper given, no verbal information. would have preferred X in for a few days, such a young child with other child and husband who is not at home much, would have preferred to be more knowledgeable need more information to prepare, hard to see your child go through this 30. on 3rd night parents went 1/2 way to emergency, changed mind child afraid to go to hospital thought through - thought not that bad, on 4th day parents again took child to hospital X awoke with blood around rim of mouth, awoke shaking & sobbing, it is very hard to bring them home nurse said you will have to be mean, not very impressed, its hard to take their role, I'm trying my best, I also have 3 year old, hard to have sick child and also have one who is very demanding, makes it difficult, its been a rough day. I suggest free counseling or pamphlet prior to day surgery have it mailed out, also suggest list of foods

33	26 prepared 2, information about postoperative care would have been good, handout before like a list of foods, problems to expect like stuffed nose, inform about how long parents need to be constantly with kids, what about if kids go to daycare, may otherwise have unrealistic expectations of parents, I didn't think it would take more than 3 days (to heal) 27. I worried about vomiting/ bleeding not being able to handle it, both my sisters experienced this, have usual anxiety. I would have liked discharge instructions ahead of time, little things like no swimming for 1 month. No inconsistencies though, they didn't tell me how it would be didn't receive enough inform to tell you if inconsistencies, it is so routine for hospitals, not so routine for me easy for mistakes 28. preferred more education myself as to what would happen, I think they go out too soon, what if had trouble, for my piece of mind, nice to have X at home
34	28. I would prefer more verbal discussion, people need to be told verbally, may not understand reading, verbal explanations need more interaction more explanation, they should notice how they treat child, X is teenager, however day surgery staff treated X as younger child, I preferred X at home, they are more comfortable at home, for tonsils not necessary overnight unless temp, soreness, X was not sick nothing serious 30. mom took X to see surgeon on 5th day, every thing good healing well, on 6th day mom called urgently home from work, X had blood gushing from mouth, by time mom got home, back of child's throat was amazingly clean - scab had fallen off
35	28. they gave good information, no inconsistencies 29. after 2 weeks Dr. will check X, no problems, I think its all good, felt comfortable having X at home, this surgery is not major operation reason why not in hospital
36	
37	27, prepared 4, completely different than other kids, this is scary, surprised X is not feeling better by now, other kids not as bad as X is, not as sickly, would have liked to see Dr. 1 wk before OR to ensure throat was not infected, wonder if X had infection 28. should have given use more instruction on what to do and what to do if, for example Tylenol 3, what to do if X won't take it or if it didn't work ,need to give more alternatives options, 29. I think kids should stay in hospital overnight, it makes sense, don't like the system the way it works, no drug stores near you to get something in the middle of the night, X was sick and they sent X home, every day crying with pain in throat, X wants to eat but hurts to swallow, would help to have list of food, X is starving
38	27. need more explanation need to talk directly with child so child understands, I didn't have chance to talk with surgeon, I really wanted to, wanted to know how my child's surgery went. Need to know more about what to expect as days go by, didn't mention ear pain, leaving you to whatever happens to your own knowing, didn't know how much fluids to give, X didn't eat much, I worried about weight loss, nurses and DR's needed to talk to X more should discuss it with child, your discussions have been very important for him, 28. I worried if I was by myself I wouldn't want to do it, had husband with me, staff not consistent not very professional, they forgot to tell us X had come back from OR, I really wanted to be there when X came in room, nursing care very lax, IV went dry they didn't keep track of it. They didn't really say much, didn't even talk to Dr., not happy with this as need to know how surgery went, what prognosis is need to know how clogged up it was, need more follow-up phone call from Dr. 29. still think regardless children should be in 1 night, no daysurgery for this type of procedure, to make sure communication between parents/Dr., gives us more time, too many things happen not enough time to prepare, too many things going through mind, I had fair bit of support, but many people don't have support, hard on them I believe, I'm thinking about the rest, it was a job and a half just to look after things. Hotel was hard, child not in own bed, to find X a meal was hard (soup), if in 1 night better, added expense for us 30. mom took child in on 6th day as concerned X might have infection, things ok
39	27. 6, I was ignorant, if prepared X would refuse to drink 1st day I would have been

	prepared, need to be prepared for this and how to get over this 28. would have preferred general run down as to how most kids are severity of pain to expect, need to answer child's questions as well. Information could be more extensive, example, what kinds of foods children can have (was really limited for selection) it was battle over past few days, give me a break -- I needed suggestions for types of food and how to prepare 29. I was really glad that you were phoning, they need to give more information need more what if situations and what would help, how to handle it, there are younger moms especially 1st time mom's with no experience or may not have had sick kids before, if don't have anyone to turn to nice to get feedback
40	28. would have helped to know that recovery is more than 2 or 3 days, Dr. gave impression, need to know when appropriate to give Tylenol, want more written information. It would be more helpful if instructions were written, I forget when under stress. Time of recovery a big one, not specifically inconsistent because they were vague, example they said give Tylenol #2 q4h then prn, need to be more specific, if I gave X as X needed or requested it, I would have given it q2h, need to know how much maximum to give 29. having you phone us was very reassuring, reassuring to know gray spots were normal, it would be good to have phone calls like this, have chance to ask questions rather than going or phoning emergency,

Case	Parent Responses to Questionnaire Items
41	27. Rated this a 6, would have preferred Dr. to explain what to expect not to panic, don't know what to expect, so make life more comfortable at home. 28. preferred staff to sit and discuss with us, Dr. should have talked to us after operation, don't know what is expected after an operation, what is normal, all of this should have been provided before operation not after 29. Worried, nurses pay attention know what is happening, I felt I didn't. No one mentioned ear ache would occur, didn't know. I think I was luck, X did good, if X didn't, it would have been panic, some parents not so luck, they would go through hell, heartache, for me easy husband helps, not that bad, X is not a cry baby, made it easier. I would have preferred X to stay in a day at least, X was cranky at first, didn't know what to expect what to look for. Thanks, you have been helpful
42	Unable to reach family 30. child admitted to rural hospital on 6th day (dehydration and hypoglycemia),
43	28. No, experienced all we were suppose to 29. Nice to know you would be phoning every day to answer any questions I forgot or had, X had plenty of time to recuperate on day of surgery 30 on 5th day dad took child to emergency dept. had intense pain in ears at night and in am
44	28. really liked it if given option to stay until doiness wore off, why not give analgesic in IV first day, then no vomiting?? Didn't know X would go without food for so long, X still hasn't eaten anything 29. No covered it all
45	28. No 29. I knew X would give me trouble, but didn't know food to give, what to give for pain They gave written sheet, I can't read it all, too tired, should have explained more didn't like it, would prefer to have both children stay in hospital 2 nights, didn't see Dr. me or children, not right we don't know if something wrong, not fair, 1st 2 days hardest especially both screaming crying, now better, but still cry and scream, don't listen to me, you were help to me, kids listen to you. 30. On 6th day mom took child and sibling (case # 46) to pediatrician to ensure no throat or ear infection, all OK
46	as above 30. As above, early unscheduled visit to pediatrician on 6th day